U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

EVALUATION OF THE DISTRICT OF COLUMBIA'S DEMONSTRATION PROGRAM, "MANAGED CARE SYSTEM FOR DISABLED AND SPECIAL NEEDS CHILDREN":

YEAR ONE REPORT

July 1998

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1. INTRODUCTION AND EXECUTIVE SUMMARY

1.0 Introduction to the Demonstration

The District of Columbia has implemented a demonstration that relies on an innovative design of a Medicaid-financed managed care system for children in the District's Supplemental Security Income (SSI) program. The operational phase of this Demonstration began on December 15, 1995 under the authority of section 1115(a) of the Social Security Act. Under this section, the District of Columbia is allowed to deviate from many standard Medicaid requirements in order to test new system designs of policy merit. In return for this greater flexibility, the District must commit to a policy experiment that can be formally evaluated.

The District's demonstration waiver authority permits them for three years to restructure the system of health care offered to children residing in the District and enrolled in the SSI program. This Demonstration tests a Medicaid payment system that includes risk sharing based on 85% risk corridors (as defined by medical loss ratios) between the District's Medicaid office and the non-profit health plan operating the Demonstration, a capitated payment system for the health plan, and negotiated fee schedules for providers. This Demonstration is offered to eligible children as an alternative to the current Medicaid fee-for-service system found in the District of Columbia. The managed care organization operating the Demonstration, Health Services for Children with Special Needs (HSCSN), offers enhanced Medicaid benefits, including individual plans of treatment, care management services, respite care, van transportation and taxi vouchers, and limited-use phones. Participation in the Demonstration is voluntary and open to all SSI recipients living in the District and under 22 years of age. Exceptions are limited to children who are also eligible for Medicare benefits (the dually-eligible) and services related to transplants.

1.1 Scope of the Evaluation

1.1.1 Summary of Workplan

The Health Care Financing Administration (HCFA) and the Assistant Secretary for Planning and Evaluation (ASPE) in the Office of the Secretary have contracted with Abt Associates Inc. to evaluate the District's demonstration.[1] The research agenda for the evaluation is broad, but comprehensive, and is best characterized as an in-depth, descriptive analysis of the Demonstration. Results of this work will increase general understanding of what factors go into designing, implementing, and maintaining this type of health care system; which children are willing to enter a health care system such as the one designed by this Demonstration; and what kinds of experiences the

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[1] HCFA Contract Number 500-96-0003. T.O. #3.

organizations, providers, and clients can expect to have when a managed care system like the Demonstration is introduced.

The work is necessarily descriptive because the Demonstration is not based on an experimental design, and the evaluation is limited in its ability to construct a comparison group. Therefore, the measurement of demonstration impacts is limited. This limitation, coupled with changing Medicaid and welfare policies and local governmental issues, demands that the evaluation be approached with creativity and use a research agenda that is flexible and responsive to what has been, and will continue to be, a very fluid research environment.

The evaluation considers not only access and cost issues, but places a considerable emphasis on issues related to quality of care and satisfaction. The research design centers on three main activities:

- analyses of the implementation of the Demonstration from which other states and managed care systems might learn how to better serve similar populations;
- analyses of enrollment which will describe which children enroll in this type of system, as well as disenroll; and
- outcomes analyses that document the experiences of the District, plan, providers, and children and their families.

The study of the implementation of the Demonstration involves an in-depth case study based on interviews, a longitudinal series of site visits to the District's Medicaid office and HSCSN, and review of the documentary record. This component of the work seeks to provide:

- **A selective, problem-directed review of the context of the Demonstration.** As the Demonstration proceeds, unexpected aspects of the environment can be expected to take on importance and impact on the decisions made by the District and HSCSN.

- **A precise description of "the Demonstration."** It is obviously essential to establish precisely what the Demonstration interventions are and are not, as actually implemented. The Demonstration is also expected to change over time as HSCSN moves from a new business enterprise, to an experienced provider of services for children with special needs, and as it reacts to a changing medical and social service environment.

- **Detailed description of demonstration processes and intermediate outcomes, to facilitate understanding of how the Demonstration could give rise to the observed patterns of results.** Other components of the evaluation (e.g., analyses of enrollment and outcomes) are likely to identify unexpected or conflicting patterns of results. To interpret these results, an understanding of the underlying processes of the Demonstration is required in order to formulate plausible hypotheses about the sources of the observed patterns. Only then can key policy questions raised by the Demonstration be answered.

Chapter 2 and Chapter 3 describe the results of the first year of work on the case study. However, the results of this work also appear in the other chapters on care management and providers and enrollment. While the context in which this Demonstration operates is extremely complex, and some of this complexity arises from a unique political environment, the context in which this Demonstration operates does not necessarily mean that whatever is learned in this Demonstration is not generalizable. Many aspects of this program are resilient to the environment such as the implications of establishing a new business enterprise to implement a federally funded demonstration. Whenever possible, the evaluators try to draw distinctions between findings that are unique to this Demonstration and those that can be generalized.

Enrollment is the evaluation's second focus because the Demonstration relies on voluntary enrollment, and understanding enrollment patterns will be critical to understanding outcomes. The District's demonstration presents an important opportunity to analyze health plan choice, and the factors important to that choice, within a population with extremely heterogenous and costly health care needs. The enrollment analyses involve two components, an analysis of the Demonstration's enrollment process, as well as determining which eligible children enroll and how they differ from those who do not enroll. Chapter 5 discusses the enrollment experience of the Demonstration as it closes its second full year of operation.

The third focus of the evaluation is to examine outcomes. The Demonstration could have a considerable range of impacts from the client level to the District level. Outcome analyses are therefore, grouped in the following way:

- **Organizational Outcomes.** The potential organizational outcomes are highly variable. However, the specific question of interest is the adequacy of the risk sharing arrangements between the District, HSCSN, and providers. This assessment can not be definitive, but an attempt is made to draw a distinction between adequate payments to an inefficient organization and inadequate payments to an efficient organization. Efficiency in this context is not be an empirical certainty, but, assessment of various measures does provide some suggestive evidence. In addition, to financial outcomes, the evaluation is also looking at the extent to which this Demonstration is able to integrate with other publicly-funded agencies serving the targeted population (e.g., schools and foster care).

- **Provider Outcomes.** The impact of the District's demonstration program on providers can be assessed at two levels: satisfaction of participating providers and impacts on the wider provider community. Provider satisfaction focuses on administrative aspects of the program and the provider fee schedule. One important issue will be the referral processes--do providers in HSCSN's network face incentives to promote or hinder the use of needed referrals? Other sources of provider satisfaction are the negotiated fee schedule and HSCSN's approach to assigning enrollees to providers.

- **Child and Family-Level Outcomes.** Because the Demonstration represents a systematic change, and the health care needs of the targeted population are extremely heterogeneous, child and family level outcomes could be wide-ranging. Therefore, analyses at this level will focus on: access and use of health care services, satisfaction, quality of care, health status, and family caregiving burden. This work relies on data collected from claims, a survey of primary caregivers, a small medical record review, and focus groups of parents.

As noted above, the ability of the evaluation to measure demonstration impacts is limited. The Demonstration does not have a random assignment design and the only comparison group involves eligibles who decide not to participate. In addition, the evaluation did not begin until after the Demonstration became operational resulting in the loss of some baseline information. These and other challenges to the evaluation necessitate outcome analyses that include strong descriptive analysis, as well as modeling and hypothesis testing when appropriate.

1.1.2 Work Completed To-Date

The evaluation has concluded its first year of work. While much of this time has been spent planning and finalizing details of the research design, a considerable amount of qualitative research has been done. However, the work that is presented in the following chapters regarding outcomes is necessarily preliminary. The Demonstration is currently on-going and outcomes observed now may not be resilient over time, or may change as components of the Demonstration change. At the levels of the District, HSCSN, and providers, intermediate outcomes have already been observed as the Demonstration has moved from its start-up phase to being fully operational. Unfortunately, at the time of this report data were not available to analyze the selection effects experienced by the Demonstration. Other than what has been obtainable through focus groups, few outcomes at the level of the child and family have been observed. As the evaluation work continues, selection effects and outcomes will increasingly become the primary focus of the work.

In order to understand the context in which the Demonstration operates and what the Demonstration is, two in-depth site visits to the District and HSCSN have been completed and were followed by interim phone interviews to clarify and confirm information obtained during the visits. During the subsequent years, the evaluation team will conduct other site visits to obtain longitudinal information, follow-up on earlier issues, and to determine organizational outcomes.

In addition to these site visits, the evaluation has begun to develop an understanding of provider level issues. Interviews at HSCSN provided information about the Demonstration's approach to the development of its provider network and care management system. Care managers were interviewed to discuss HSCSN's unique care management system. Numerous interviews with providers have been completed to obtain information on the incentives faced by providers and how they participate in HSCSN's care management system. In succeeding years of the evaluation, this work will continue and will more fully focus on provider outcomes such as satisfaction and changes in practice patterns.

The evaluation has also conducted its first set of focus groups with parents. These groups were composed of five groups of parents with children in the Demonstration and one group who declined demonstration services. These groups discussed parent reaction to the Demonstration's marketing and outreach efforts and the elements that went into their enrollment decision. During these groups the evaluators heard some reaction to demonstration services. However, parent satisfaction and changes in family caregiving burden will be explored more fully in subsequent focus groups.

During the first year of the evaluation, quantitative analyses were limited. Secondary data sources are large and complex and the process of obtaining these data is time consuming. The primary data collection efforts, the medical record abstraction and the survey of primary caregivers, were only in the planning stages during the first year. It is anticipated that these data collection efforts will begin in the next year. Despite these limitations, the evaluation has been able to document demonstration enrollment patterns and conduct preliminary sketches of children entering the Demonstration.

1.2 Executive Summary

The following section highlights some of the interim findings that the evaluators found during the first year of work. During this first year the objectives of the work were to determine the context in which the Demonstration operates and what the Demonstration is, as opposed to what was planned or described in documents. The findings of this work are presented more fully in Chapter 2, Chapter 3, and Chapter 4. Knowing what the Demonstration is as implemented provides substantial background for Chapter 5 which presents the enrollment experience of the Demonstration after 22 months of operation.

1.2.1 What The Evaluation Knows So Far

Most demonstrations are developed and operate in circumstances that are unusual or atypical. What is striking in the District is how fundamental some of these circumstances were and continue to be. The planning and start-up phases of the Demonstration began in a context that had the following features:

- **Severe costs problems in the Medicaid program.** The DC Medicaid program was facing severe cost problems in the early 1990s. It was the fastest growing health program in a city facing fundamental fiscal crisis. By 1994, as the Hospital for Sick Children (HSC) was reviewing the possibilities for managed care for children with special needs in the District, the District Medicaid program was making early policy commitments to capitated solutions for a series of high-cost Medicaid services, thought to be at the heart of the cost problem: long-term care, substance abuse, and mental health/mental retardation. When the HSC proposal for a demonstration came, the Medicaid program (Commission on Health Care Financing, or CHCF) was in many ways prepared for it.

- **The targeted population was thought to be poorly served.** One Medicaid official we interviewed suggested that the District has "awful" statistics on preventive, chronic, and long-term care. The organization and financing of District human services was thought to be partly responsible. A proposal to integrate services for children with special needs thus offered help in an area that the District was believed to need help.

- **Some of the principal agencies did not have close working relationship before the Demonstration.** The key players in putting the Demonstration together--principally, the Commission on Health Care Finance of the District of Columbia (CHCF), the Hospital for Sick Children (HSC), and the Health Care Financing Administration's Office of Research and Demonstrations (HCFA/ORD)--had not worked closely together prior to this initiative.[2] This is not unusual for local demonstrations operating under waivers approved by HCFA. However, it increases the potential for misunderstandings and unexpected delays, which were an important factor here.

- **Major changes in the surrounding context occurred.** As waiver negotiations began in earnest, DC finances worsened. The federal price for resolving this continuing crisis was a substantial reduction in home rule powers. The increasing powers of the outside Control Board imposed by Congress threatened to change the politics and administration of the District government in large and small ways. Meanwhile, somewhat independent of that upheaval, the Medicaid program itself was about to change: a relatively small, optional managed care program for mainstream Medicaid enrollees was about to become mandatory for all mainstream enrollees in 1997. While children with special needs were carved out of the mandate, the commitment of the Medicaid program to managed care had spread substantially from the early days of planning for the Demonstration.

From this context came a unique waiver application for a demonstration; a new business enterprise would be established and it would operate a managed care system for children living in the District and participating in the federally-funded SSI program. The waiver application process was long and tense, one result of this process was an

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[2] HSC was a Medicaid provider and thus had routine exchanges with the Medicaid intermediary. CHCF, and HCFA prior to the Demonstration. CHCF was the administrator of the Medicaid program for the District and thus had frequent contact with HCFA and providers in that role. Those activities provided some foundation for the Demonstration activities, but District and HSC/HSCSN respondents generally seemed unfamiliar with HCFA staff or waiver negotiations.

enrollment process that underwent several design changes. In addition, because the community at-large was not involved during the early design stages, community opposition made the application process more difficult. The evaluators can at least offer the following tentative implications for other states and entities considering this kind of model:

- The waiver approval process has undergone many modifications in recent years, including new provisions contained in the Balanced Budget Act of 1997. The difficulties of the waiver negotiation process for this Demonstration should not be generalized too quickly as a result. But at least a mild suggestion is obvious: no state or local entity that must receive HCFA approval for reform or demonstration initiatives should assume approval or a timeline for an approval, absent discussion with HCFA.

- That conservatism is especially important when the review process must resolve some fairly substantial issues, issues that in this case were evident almost as soon as the application was submitted. The original design proposed in this Demonstration contained unusual restrictions on beneficiary choice: mandatory enrollment in a single health plan that, although related to a substantial health provider for this population, had no experience doing what it proposed. These restrictions were for care of a notably vulnerable indigent population with substantial service needs. This proposal posed a particularly difficult form of the restriction, especially in view of the requirements in the Americans with Disabilities Act (ADA). That difficulty was reflected in the complexity of the discussions that followed.

- This Demonstration faced political and community opposition that could have been reduced if the District and HSCSN had followed fairly rudimentary forms of consultation. The District itself concedes that it should have done more, earlier, to consult the community--and parents, in particular. As it was, parents were uninformed, and that made them more vulnerable and naturally worried about rumors (some rumors apparently orchestrated by providers) concerning the new Demonstration. Many parents who were opponents later became proponents (two now sit on HSCSN's board), but only after extended efforts to explain the Demonstration. That the parents could be persuaded suggested how valuable it would have been to involve them up front. For obvious reasons, HCFA paid close attention to parents' complaints--and those could have been derailed by earlier contact with parents, in the opinion of District demonstration staff.

Managed care systems can be implemented in many different ways, particularly where, as here, the venture is without extensive precedents, long-established protocols, or settled standards of monitoring and review. To understand the Demonstration and its effects, it is obviously essential to establish precisely what the Demonstration interventions are and are not, as actually implemented. The Demonstration plans are clear enough, but many different versions of the Demonstration could follow from those plans. The intervention must be mapped with care to establish a foundation for the implementation analyses, as well as to document processes of the Demonstration to support inferences and interpretations of other data (e.g., survey results and utilization analyses).

The Demonstration intervention can be divided into the following three different areas:

1. **Risk sharing and the concept of managed care for children with special needs.** The risk sharing arrangements specify that the organization operating the Demonstration, HSCSN, receives from DC Medicaid a per member per month capitated payment. Individual providers are not paid a capitated rate, but from a fee schedule that HSCSN has separately negotiated with each provider. Any profits and or losses experienced by HSCSN are shared between HSCSN and DC Medicaid based on 85% risk corridors. The basic premise implied by this risk sharing arrangement is that the organization operating the Demonstration has the incentive to manage care actively, in a way that no public agency or fee-for-service provider would be able to do. While Medicaid and other systems imposed limits on utilization and coverage in various ways (e.g., prior authorization requirements), no one in those systems was empowered to take responsibility for the active management of individual cases--e.g., to assist in scheduling appointments and arranging transportation, to coordinate different treatments, to eliminate critical barriers to care (such as physical impediments in housing), and to refine and adapt overall programs of treatment. HSCSN uses care managers to play this active integrating, coordinating role. The key challenges to the care management system are to augment services in cost-effective ways, to integrate health and social support systems, to establish linkages across different types of demonstration and non-demonstration services, and to facilitate access where key barriers to care impeded cost-effective use of preventive and other services.

2. **The Benefit Package.** In this Demonstration, HSCSN is required to provide the full panoply of mandatory and optional Medicaid benefits available in the District, including inpatient hospital, nursing facility, intermediate care facility for the mentally retarded, outpatient, physician, family planning, dental, prescription drug, home health, vision care, transportation, mental health/substance abuse, hospice, and other services. But HSCSN enhances this package. They include 24-hour care management services which are perhaps the defining characteristic of this Demonstration. The implied premises of the Demonstration are that *this is the most important benefit of all*, since it is the process of obtaining care that has been the primary frustration of parents of children with special needs. With prior authorization HSCSN also provides: limited-use telephones, transportation to appointments, home modifications, feeding and nutritional programs, respite care, and expansion of home health care, medical supplies and equipment, dental services, and physical, occupational, and speech therapy consistent with habilitative and rehabilitative needs.

3. **The Organization.** This Demonstration involves the introduction of a new, non-profit business enterprise into the District's health care system. As a new entity, HSCSN has seen not only growth in staff, but a restructuring as it moved through the phases of design, start-up, and being fully operational. Had the Demonstration relied on a previously established managed care organization, management structure might have been more stable and the objectives of the entity operating the Demonstration might have been clearer. In the case of this Demonstration, the parent company invested a substantial amount of funds during the planning and start-up phases. It is not necessarily clear to what extent this funding was provided as a strong and benevolent commitment to deliver managed care benefits to children with special needs in the District or that the parent company (and now HSCSN) viewed the Demonstration as a strategic business decision to insure its survival in a new competitive environment. Both are likely organizational objectives. Regardless of the precise nature of organizational objectives, HSCSN has developed an information management system that is based on systems for the following five operational areas: payment, quality management, credentialing, internal networking (e.g., email), and care management. The first four were relatively easy and relied on offthe-shelf products. The fifth system, critical to HSCSN's role as an integrator, has been difficult and as of this report, was in its final planning and design phase. The absence of any adaptable system on the market suggests that the kind of care management envisioned is indeed different. That HSCSN sought to develop a more sophisticated technical infrastructure for care management suggests a longer-term view of the Demonstration and a commitment to putting in place a new care management technology for service well beyond this Demonstration.

Because this Demonstration does not make use of traditional management techniques such as capitated payments to providers, physician gatekeepers, or penalty co-payments for the inappropriate use of services such as emergency rooms, one focus of the evaluators has been to determine how care is managed in this Demonstration. We find that care is managed by a system that relies heavily on HSCSN's care management system and its network of providers.

- **HSCSN's Care Management System.** HSCSN care management employs an innovative staffing model that is designed to accommodate children with a variety of needs and levels of severity. The three care management teams are each lead by a senior, experienced health professional: one nurse, one clinical social worker, and one occupational therapist. Under each team leader, there are care managers who are experienced professionals, including nurses, social workers, and therapists--a mix of professions and experiences on each team. Under each team leader, there are also care manager associates, who have a B.A. and a variety of work experiences, including administrative jobs in health-related organizations. There are currently three team leaders, seven care managers and twelve care manager associates. All three types of personnel are referred to as "care managers" by HSCSN staff, providers, and members' families.

Care managers at all levels--even those with very specialized training--emphasize the multiple non-medical needs of most members' families and the importance of addressing these so that the child can benefit from a stable home environment. They spend much of their time educating families about, and helping them use, appropriate sources of health care. Care managers believe that the children who can benefit most from the HSCSN care management program are not necessarily the most medically complex, but those who have multiple needs, including behavior problems.

Assessments of new members are reviewed at team meetings, during which each new member is assigned for care management. The criteria for assignment are level of medical acuity, and type and complexity of service needs. The most complex are assigned to the team leaders: the most medically complex members to the nurse, the most serious mental health problems to the social worker, and children with the most serious functional problems or rehabilitative needs to the therapist. The team leaders, who handle the most complex needs, have the smallest caseloads, ranging from 35-40. A child in the mid- range in terms of acuity would be assigned to a care manager, and, again, the specialty of the care manager would be matched to the needs of the child: for example, a child who uses a feeding tube would be assigned to a nurse, and a child with behavior problems would be assigned to a social worker. Caseloads at this level range from 50-80. A child with less severe problems would be assigned to a care manager associate. Caseloads at this level range from 90-140.

Care managers must develop a plan of treatment (PoT) based on an assessment, but, recognizing the limitations of the assessment process, they consider the PoT to be a living document from the start, to be revised when more information is learned by the care manager and when the PCP has examined the child. A completed PoT includes goals, prescribed services and planned care management activities for: preventive care; nutrition; functional skills; education/vocation; and support/education for member, family, and caregivers. PCPs may receive PoTs in advance of medical records. When evaluators interviewed PCPs, they were found to be less bothered by the weaknesses of the assessment and PoT development process than the care managers. PCPs generally said that the PoTs were a good start and provided more information than they often had about a child.

There was notable agreement among care managers and providers that the speed of the HSCSN authorization process had an especially favorable impact on the timely provision of durable medical equipment (DME). One DME provider pointed out that braces and other equipment have to be customized to fit growing children. The authorization process for conventional Medicaid coverage could take so long that in the time elapsed the child could grow sufficiently to require a new fitting for the needed equipment. That the HSCSN authorization process for equipment under $2,500 could be completed in a couple of days was considered by many to be an important outcome of the program.

- **Reactions to the Care Management System.** The general trend found in our interviews was: the more frequent the contact between provider (or provider's employee) and care managers, the more favorably impressed the provider would be with the care management system and HSCSN services overall. We know little about the reactions of families to this system, but what we have heard is favorable.

- **The Provider Network.** In recruiting providers, a strong selling point was the care management program. Some physicians had been reluctant to serve Medicaid patients and many had been unwilling to increase their Medicaid caseloads. They were concerned that the time required for physicians' office personnel to contact families and follow up on appointments to increase compliance, and to address urgent non-medical needs that interfered with their medical treatment, could not possibly be covered by Medicaid reimbursement. HSCSN offered them a care manager to address these needs.

  In most cases, HSCSN offered better rates than conventional Medicaid, although some smaller specialty providers that we spoke to claim that this was not the case. Some complained that rates were still too low, even though they were higher than those of conventional Medicaid. HSCSN also had intended to reimburse PCPs for some interactions with care managers, but there appears to be a lot of confusion about this, and it is not clear if many PCPs are sufficiently well-informed to know how to bill for this payment. Evaluators have not found a description of this policy, or the billing procedure in the HSCSN Physician Manual. HSCSN also promised timely payment. Most providers we spoke to found that they delivered on this promise. Others commented that they had not had a serious problem with timeliness of conventional Medicaid payments, but that the regular Medicaid program often made mistakes in payments (resulting from inaccurate entering of codes) and these could take months to correct. No provider reported that problem with HSCSN.

- **Provider Experiences.** In general, PCPs in the network are more satisfied than physician specialists, for several reasons. First, providers who have more contact with the care managers, and with HSCSN in general, tend to be more satisfied. The care management process requires frequent contact between the care manager and the PCP, or at least with the PCP's office. In most cases, this seems sensible because the PCP has much more contact with, and a broader range of responsibilities for, the child. However, some children also see a specialist regularly, and the formal process does not require more interaction with the care manager for these specialists. In addition to having less communication with care managers, specialists claim to be less frequently contacted by HSCSN, and sometimes they claim to have negotiated less favorable rates and working arrangements with HSCSN than the PCPs.

Another reason for less enthusiastic responses of specialists is that HSCSN follows the by-now customary managed care strategy of encouraging prevention and primary care while looking for opportunities to decrease--or at least control more closely--the use of expensive specialty services. A typical example is the psychiatrist who maintains that he is only used for prescriptions while less expensive mental health practitioners provide ongoing care, and some behavioral issues that he might want to address are handled by the PCP.

The perceptions of specialists are clearly different from those of PCPs, as some specialists quickly conclude that PCPs have "more to gain" from the HSCSN approach. That some PCPs refer to the HSCSN program as "the only game in town" if one wants to serve this population, reinforces the perceptions of some specialists that PCPs are anxious to please HSCSN, and therefore some of their care decisions may be suspect. These perceptions are not conducive to team building, and there do not seem to be any system requirements or incentives for team interaction beyond care manager/PCP contact.

When providers were interviewed, if they had experience with conventional Medicaid, they were asked to compare care delivered in the conventional Medicaid program with care delivered by HSCSN. Most providers believed that HSCSN delivered more primary care and did a better job of screening children. If providers interviewed had experience with other managed care organizations, they were asked to compare care delivered by those organizations with care delivered by HSCSN. In most cases, HSCSN was said to be comparable or better. In view of the hundreds of children served by these providers--and many of the providers have been with HSCSN since the beginning of the Demonstration-- there were surprisingly few instances in which requests for a service had been challenged, much less denied. One denial of service that was described--involving a request for cosmetic surgery to address self-esteem issues--had left both a PCP and a specialist with a negative impression of HSCSN.

Problems surfaced at two major Washington D.C. institutions that are in the HSCSN provider network. At the provider level, HSCSN appears to have a good working relationship with a D.C. General clinic (which is not a public health clinic) that provides services to children with special needs. But at the management level there are issues. HSCSN attempted to include the public health clinics operated by D.C. General, but ended this effort when the unionized providers in them refused to allow their credentials to be examined.

Children's National Medical Center is the other institution at which problems surfaced. Initially, we interviewed at the management level at Children's, where we found general satisfaction. We also interviewed employees of two Children's physician specialty practices, who had extensive contact with HSCSN care managers, and we heard positive comments from them. Finally, we talked to the

> physicians who facilitate the primary care services provided to HSCSN by Children's, and there we heard about a number of problems.
>
> Children's insists on assigning PCPs to the enrollees so that they can distribute the workload reasonably. Also, primary care physicians at Children's are said to have less nursing support and fewer administrative personnel than the specialists at Children's. They therefore have to communicate personally with the HSCSN care manager, and they believe that HSCSN should provide at least a part-time on-site care manager at Children's. This may or may not be a good solution for HSCSN, but the Children's PCPs feel strongly that the possibility has to be seriously entertained. They would also like all authorizations to be made by the PCPs, not by the HSCSN care managers. The physicians we spoke to did not address the issue of sharing risk, nor have they discussed this with Children's management, which is likely to be more sensitive to the issue of linking authorization decisions to the assumption of risk. The Children's PCPs also have noticed that some HSCSN care managers want to authorize visits to specialists (often outside of Children's) that members visited prior to enrolling in HSCSN. They believe that many of these conditions could be monitored successfully by PCPs at Children's. In effect, the Children's PCPs believe they have most necessary services under their own roof, and they want to function in a manner that would approximate a staff-model HMO; while HSCSN is asking them to be part of a larger network and to follow rules designed for a dispersed network of providers.

As outlined above, the Demonstration involves the creation of a new business entity and the introduction of a partial risk sharing system that relies heavily on an innovative care management approach. What has been the reaction of the targeted population? In February 1996, the first eight children began receiving services from HSCSN. As of November 1, 1997, monthly enrollment stood at 1,901 children, representing about 71% of the eligible children that have been located. During the 22 months of operation, the Demonstration has served a total of 2,089 different children and has experienced a total of 26,286 member months.

At 71% of located children and little disenrollment due to dis-satisfaction, demonstration enrollment appears to be very successful. However, achieving this success has not been easy. The most important problem faced by the District and HSCSN has been identifying and locating a large proportion of the population believed to be eligible for program services. In addition, the initial enrollment materials have not been particularly effective in eliciting enrollment, consequently during the planning phase, the District and HSCSN had not fully anticipated the amount of time and resources necessary to market the program. Now during a period of stable enrollment, HSCSN views the enrollment process as manageable, but unexpectedly problematic. Lastly, many families appear not to realize that enrollment in the Demonstration is voluntary. This lack of awareness may result from an enrollment process that is ostensibly operated by HSCSN and enrollment materials that inaccurately state that if the family does not respond to the enrollment mailing, then the child will be automatically enrolled in the Demonstration.

1.2.2 Future Areas of Investigation

Our work on the context and origins of the Demonstration is substantially done. One principal task remains:

> **Selective data collection from all demonstration partners, as new issues arise:** As the Demonstration proceeds and our evaluation expands, unexpected aspects of the environment will take on additional importance, and the evaluation must be alerted to collect data intensively in these areas. Thus, for example, utilization patterns may exhibit pre/post variations that make an understanding of pre-demonstration patterns more important to document; or difficulties in collaborating with potential partners (e.g., the schools) may increase the importance of understanding the early decisions made by the CHCF, HSCSN, and the District schools. We will do data collection as needed on these issues.

More generally, however, the focus of our future work will be not on the origins and context of the Demonstration, but rather on its implementation. Key areas of data collection and analysis in this area will focus on seven general areas of interest.

1. The evolution of HSCSN as an organization, including staffing, priorities, and financial performance.

2. The effects of personnel changes at HSCSN and CHCF. These changes may influence the relationship between these two entities. To the extent that the collaboration between CHCF and HSCSN is due to the novelty of the initiative, we might see the development of more formal standards of monitoring as the protocols or operation become better understood. In any event, if any problems are revealed in the performance of the contractor, it will be important to reexamine the CHCF-HSCSN relationship to understand whether anything in that relationship contributed to the problems.

3. The developing understandings between HSCSN and related service systems, including the Commission on Mental Health and foster care. One of the most important related service systems is the school system. The school system may have reasons for avoiding collaboration with the Demonstration that are critical to the Demonstration. Such information could change our understanding of how CHCF and HSCSN went about the work of coordination with other service systems.

4. The financial performance of HSCSN, including documentation of risk-sharing calculations for all years, audited results for HSCSN for years after 1996, and areas of major cost savings against baseline data. If HSCSN does not continue to break even on a cash basis, our tentative confirmation of the practicality of the principal assumptions of the Demonstration will have to be reconsidered.

5. The implementation of any new care management system, with a particular emphasis on documenting how the system changes care management staffing, procedures, and accomplishments. The basic care management system appears to be stable and well- designed for this Demonstration. It could ultimately have an impact on care, but it is not as apparent that it will have an impact on reducing costs. The current belief at HSCSN appears to be that an emphasis on primary care, coordination of services, and supportive services, with close review of the most expensive services, will be cost effective in the long term. If that approach works, how will it work? Among the possible explanations are:

   - Children who formerly received no regular primary care will make fewer visits to the emergency room and have fewer acute episodes.
   - Coordination of care will avoid duplication of services and the provision of unnecessary services.
   - Improved knowledge of a member's needs, gained from monitoring, will lead to the provision of more appropriate services.
   - Provision of supportive services, and resolution of non-medical issues, will enable the member to get the maximum benefit from medical care.

   Any change in philosophy at HSCSN should be evident in the care management program and in the ways that care managers interact with providers. For example, a more explicit focus on cost containment might immediately impact on the way that care managers spend their time and on the services they authorize.

6. The provider network and provider relationships with HSCSN management and care management system. Relative to the care management system, provider arrangements are not as stable as one might expect at the moment. Issues of dis-satisfaction among the PCPs at Children's could have serious consequences if they are not resolved, given the importance of that institution in the Demonstration. Outside of Children's, specialty provider issues noted are not unusual in a managed care program. They are probably not threatening to the program, but could be addressed. In general, communication with providers, and how providers communicate and interact with care managers can be worked on. Arguably the change that could make the most difference would be if HSCSN initiated risk-sharing arrangements with providers. This would address concerns about incentivizing providers, but decision making strategies might have to be reexamined. Whether or not the PCPs have "really" been making the medical decisions all along, would become an active issue, as would any inclination on their part to make different decisions when their incentives are changed.

7. The estimation of the frequency and context of utilization of certain enhanced benefits in this Demonstration (e.g., telephones, residential modifications, and home care) to explore how much, if any, change in utilization is due to the expanded continuum of benefits being provided. If our utilization analyses failed

to confirm the changes in utilization being used to explain demonstration savings, we would need to reexamine how HSCSN was able to save money.

Beyond these research issues on the implementation of the Demonstration, the evaluation must now begin to focus more closely on outcomes, and to understand these outcomes we must begin to understand the extent and direction of any selection effects experienced by the Demonstration. Understanding which children have entered the Demonstration and which remain in the fee-for-service system will influence how HSCSN and the District adjust features of the Demonstration, and how providers and children and their families experience and benefit from demonstration services.

2. THE CONTEXT OF THE DEMONSTRATION AND ITS ORIGINS

2.0 Introduction

The Managed Care Demonstration for Special Needs Children (hereinafter, the "Demonstration") moved forward in an unusual context:

- **in a Medicaid program with severe cost problems.** The DC Medicaid program was facing severe cost problems in the early 1990s. It was the fastest growing health program in a city facing a major fiscal crisis. By 1994, as the Hospital for Sick Children (HSC) was reviewing the possibilities for managed care for children with special needs in the District, the District Medicaid program was making early policy commitments to capitated solutions for a series of high-cost Medicaid services thought to be at the heart of the cost problem: long-term care, substance abuse, and mental health/mental retardation. When the HSC proposal came, the Medicaid program (administered by the District's Commission on Health Care Finance, or CHCF) was in many ways prepared for it.

- **for a target population thought to be poorly served.** In the words of one District Medicaid official we interviewed, the District has "awful" statistics on preventive, chronic, and long-term care. The organization and financing of District human services was thought to be partly responsible. A proposal to integrate services for children with special needs offered help in an area that the District recognized was in need of help.

- **by agencies that did not have close working relationships before the Demonstration.** The key players in putting the Demonstration together--principally, the Commission on Health Care Finance of the District of Columbia (CHCF), the Hospital for Sick Children (HSC), and the Health Care Financing Administration's Office of Research and Demonstrations (HCFA/ORD)--had not worked closely together prior to this initiative.[3] This is not unusual for local demonstrations operating under waivers approved by HCFA. However, it increases the potential for misunderstandings and unexpected delays, which were an important factor here.

- **just as major changes in the surrounding context were about to occur.** As waiver negotiations began in earnest, DC finances worsened. The federal price

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[3] HSC was a Medicaid provider and thus had routine exchanges with the Medicaid intermediary, CHCF, and HCFA prior to the Demonstration. CHCF was the administrator of the Medicaid program for the District and thus had frequent contact with HCFA and providers in that role. Those activities provided some foundation for the Demonstration activities, but District and HSC/HSCSN respondents generally seemed unfamiliar with HCFA staff or waiver negotiations.

for resolving this continuing crisis was a substantial reduction in home rule powers. The increasing powers of the outside Control Board imposed by Congress threatened to change the politics and administration of the District government in large and small ways. Meanwhile, somewhat independent of that upheaval, the Medicaid program itself was about to change: a relatively small, optional managed care program for mainstream Medicaid enrollees was about to become mandatory for all mainstream enrollees in 1997. While children with special needs were carved out of the mandate, the commitment of the Medicaid program to managed care had spread substantially from the early days of planning for the Demonstration.

Most demonstrations move forward under at least some apparent circumstances that are unusual or atypical. What is striking in the District is how fundamental some of these circumstances were. In the chapter that follows, we will review the context and origins of the Demonstration in greater detail, to set the stage for a summary in the next chapter of what the Demonstration intervention came to be. To help structure this discussion, a timeline for significant events in the origins and implementation of the Demonstration appears in Figure 2-1.

FIGURE 2-1. Managed Care Demonstration for Children with Special Needs: Demonstration Milestones

Year	Month	Milestone
1993	May	Hospital for Sick Children (HSC) hosts the National Association of Children's Hospitals and Related Institutions (NACHRI) conference where the idea of a managed care system for disabled children is raised
	June	Initial HSC review is favorable
1994	January	Results of feasibility study reported to HSC board members
	February	Health Services for Children with Special Needs (HSCSN) is incorporated
	March	Commission on Health Care Finance (CHCF) submits an 1115 waiver application to the Health Care Financing Administration (HCFA)
	April	HSCSN applies for not-for-profit status (received in May)
	August	District receives one year Development Grant from HCFA
		[Startup date forecast by HSCSN]
1995	July	CHCF public forum for families of children eligible for proposed demonstration
	October	Waiver approved
	December	Three-year Demonstration formally begins December 1. Mailing of notification package to first group of beneficiaries delayed until mid-December, to permit required HCFA review of materials and resolution of outstanding operational issues.
1996	February	First covered services for enrollees
1997	May	Joint Commission on Accreditation of Healthcare Organizations conducts on-site survey. HSCSN granted 3-year Accreditation.
	November	Startup for new care management information system. End of Second Year of the Demonstration. 1,901 enrolled members (11/1/97)
1998	November	End of Demonstration on November 30.

2.1 The DC Medicaid Program

2.1.1 Organization

Until recently, public support of health and social services in the District has been administered through four separate commissions (GAO, 1996):

- **Commission of [sic] Public Health** (CPH), which sets public health care policy, administers the District's preventive care and alcohol and drug abuse service programs, and provides health services directly at a District nursing home and public health clinics.

- **Commission on Health Care Finance** (CHCF), which sets Medicaid policy and administers and finances the Medicaid program.

- **Commission on Mental Health Services** (CMHS), which administers the District's mental health care system, including St. Elizabeth's hospital.

- **Commission on Social Services** (CSS), which processes applications to determine applicants' eligibility for Medicaid and other social programs.

In addition to the activities of the four commissions, the District also provides public health services to all District residents at D.C. General Hospital.

Until 1996, these four commissions were part of the Department of Human Services (DHS), as shown in Figure 2-2. However, under a 1996 reorganization, DHS was split into a Department of Human Development (later named the Department of Human Services) and a Department of Health. This reorganization came at the same time as the District's fiscal crisis intensified, but the reorganization grew out of internal plans to create a consolidated Department of Health, rather than from directives of the Control Board.[4] As the agency responsible for the Medicaid program, CHCF was also the agency responsible for this Demonstration. The reorganization of DHS suggests that there was some administrative instability around the time of the implementation of the Demonstration. (Later, in 1997, there was another reorganization affecting the Demonstration, when the Demonstration was moved to a new Children's Unit in CHCF.) There also were important personnel changes in this period: for example, the person who was Commissioner of CHCF when HSC and CHCF began discussions left in 1995 to join HSCSN. But there have been important sources of stability: e.g., the project officer in CHCF had uninterrupted oversight of the Demonstration from May 1995 to late 1997, when control shifted to the new Children's Unit.[5]

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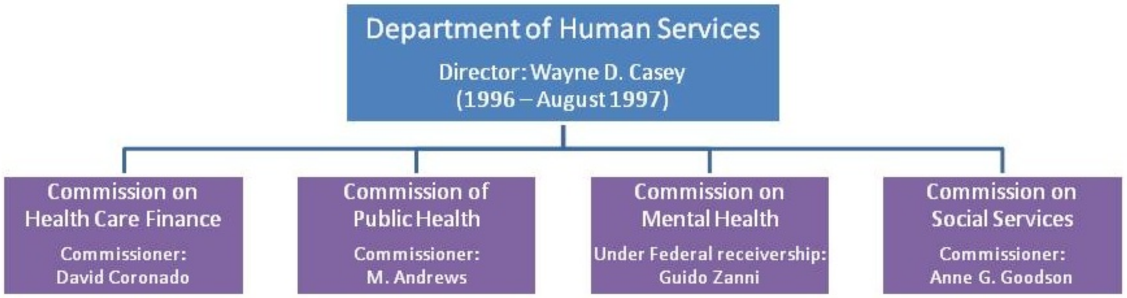
[4] In due course, however, the Control Board reorganized the Department of Human Development created by this 1996 reorganization.

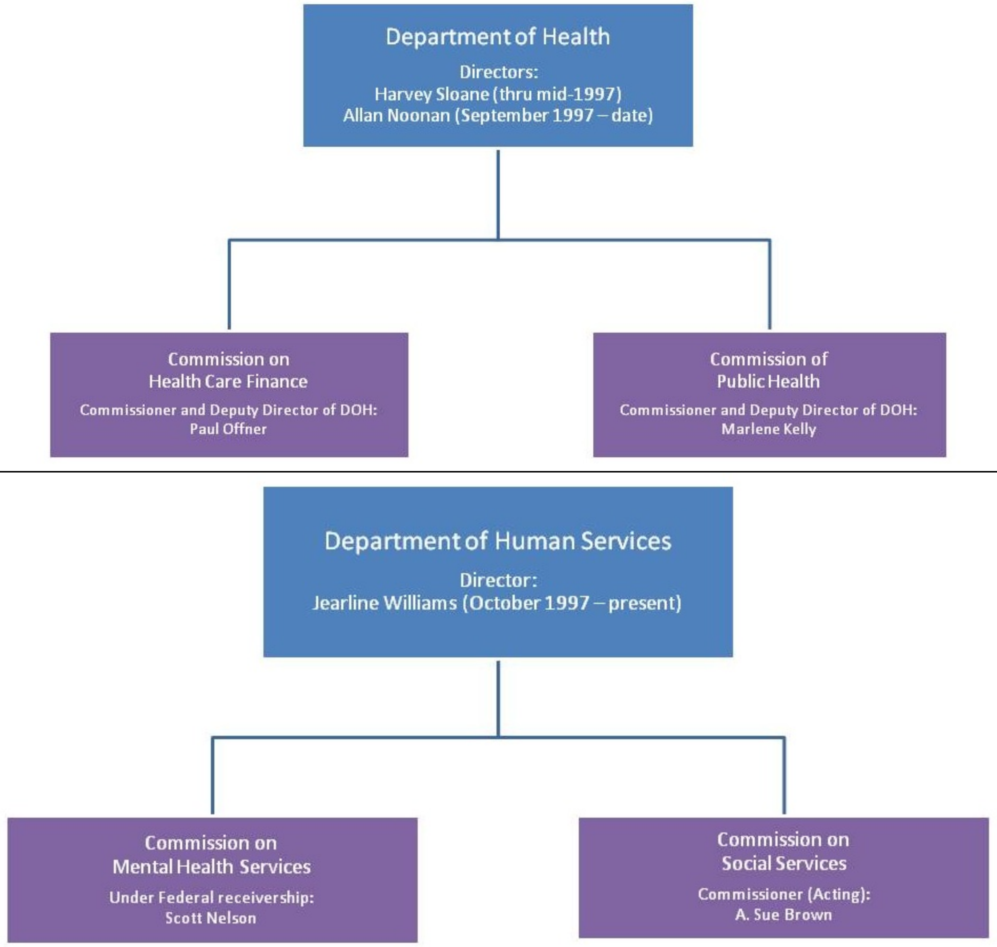
[5] District oversight has not been stable since that first change, as oversight passed to a third project officer in early 1998.

FIGURE 2-2. Organization Charts for District Health and Social Services

DC Organization Prior to August 1996



DC Organization From November 1996 - Present



2.1.2 Expenditures

Overall, the District's health care expenditures increased approximately 25% from fiscal years 1991 to 1994 (GAO, 1996).[6] In fiscal year 1994 (the year during which planning for the Demonstration began), health care expenditures in the District totaled

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[6] All expenditure data in this paragraph are taken from this useful GAO report. Note that the DC fiscal year is the same as the federal fiscal year A(October - September).

$1.246 billion, which represented approximately 27% of total District expenditures for the fiscal year. The Medicaid program alone cost $768 million in that year, or 62% of all health care expenditures and one in six dollars spent by the District.[7]

Not only was the Medicaid program large, it was also "the District's fastest growing health care program" (GAO, 1996, p.3). According to the GAO report, over the four fiscal years from 1991 to 1994, Medicaid program expenditures increased approximately 53%. This large increase actually was not so unusual: consider that, over this same period, Medicaid expenditures increased 53% nationwide. Nevertheless, amidst the growing District fiscal crisis, the growth in Medicaid expenses stood out: expenses for mental health services, D.C. General, and public health programs were more stable, increasing between 7% and 17%.

For all this expense, the District Medicaid program addressed the needs of a population that had staggering health needs. In 1994, the District was *fifty-first* out of all the states in key indicators of physical and emotional health, such as rates of low birthweight babies, infant mortality, child deaths, teen deaths by accident/homicide/suicide, teen births, and juvenile violent crime arrests (e.g., see Casey Foundation, 1995). Depending on one's point of view, these statistics could either explain some of the high cost of the District Medicaid program or point to the failures of the costly program to support the health of the people it served.

We do not know the data that CHCF had available in the early planning years of the Demonstration. However, there is evidence that the Commission was, among other things, especially concerned about the costs of serving special populations. The District's strategy for controlling Medicaid costs in the midst of the financial crisis included:

- The introduction (in April 1994) of managed care for the District's AFDC-based Medicaid population under a Section 1915(b) waiver. AFDC beneficiaries were given a choice of either (1) a managed care organization, or (2) fee-for-service with a primary care case manager. In late 1996, an RFP was issued to move the non-disabled Medicaid population to mandatory managed care enrollment. Under this expanded program, the District planned to pay two flat capitation rates: one for adults, one for kids. Four plans were selected in 1997, but protests from

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[7] Note that other sources give different expenditure figures for the District Medicaid program, but show expenditure increases of a similar magnitude. For example, a major District planning document (District of Columbia, 1997), shows FY 1991 Medicaid expenditures totaling $427.0 million and FY 1994 expenditures totaling $662.7 million, an increase over this period of 55%. Such differences in data are a recurrent problem in describing health programs in the District: there are discrepancies among different data sources. (On this point, see also GAO, 1996.) Some of these discrepancies are not important for our purposes. However, some discrepancies are central--e.g., as we will discuss later in the text, staff at the Hospital for Sick Children (HSC) and an HSC consultant (Lewin-VHI) discovered that the eligibility files for children with special needs contained substantial inaccuracies, such that is was impossible to determine with confidence the number of children historically eligible for this benefit and where these children were located. It was accordingly difficult to estimate historical costs per eligible (on which to base future capitation payments) or physically to locate members of the target population for the Demonstration. We will discuss these issues and their consequences later in the text.

losing plans have suspended the mandatory enrollment program for the time being.

- The development of capitated managed care organizations for high-cost populations: long-term care, substance abuse, and mental retardation/mental health.
- The implementation (April 1995) of DRGs for inpatient payments.
- New measures to encourage the use of outpatient surgical settings.
- The introduction of one-day inpatient surgery pre-admission certification.
- The implementation (January 1996) of more active management of very expensive substance abuse admissions.[8]

These planned and actual initiatives were beginning to turn the District's Medicaid program from a fee-for-service-based program to a managed-care-based program, much as in other states at this time. While children with special needs were carved out of the mandatory managed care initiative,[9] a managed care demonstration for these children with special needs was a relatively harmonious fit with the evolving policy commitments elsewhere in the Medicaid program, as the Demonstration was designed, approved, and implemented from 1993 through 1996.

2.2 The Fiscal and Political Crisis in the District

These revised strategies for the Medicaid program were developed in the midst of a substantially worsening political environment in the District. There is debate over the roots of the crisis,[10] and we are in no position to resolve that debate. For our purposes, the important point is that the crisis was brought to a head by the worsening finances of District government. In 1993, budget pressure led the city to adopt what were viewed by many as "questionable budget and accounting practices" to cover up underlying deficits (Powell, 1997).[11] By 1995, deficit pressures remained substantial, and the District's

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[8] Data at the time showed that just a few substance abuse cases could generate enormous costs; e.g., in one year, only 15 cases generated $500,000 in costs.

[9] Children with special needs who did not enroll in the Demonstration could continue, as before, to obtain services under fee-for-service arrangements. This special needs option was one of the few remaining fee-for-service options planned for the District Medicaid program under the mandatory managed care plan that was to go into effect in 1997.

[10] Some (e.g., leading Republican members of Congress and others) blamed the District's government for failing to take strong action to meet the fiscal crisis. Others (e.g., leading politicians and advocates in the District) pointed to the structural causes for the crisis, such as the flight of the black and white middle class from the city. Among many sources, see Harden (1997).

[11] For example, in a one-time infusion of tax receipts, Mayor Kelly adjusted the city's property tax year in 1993 back three months, thereby in effect using 15 months of receipts to fund 12 months of spending.

relations with Congress had changed: Mayor Barry was reelected, there was a new Republican majority in Congress, and at least some members of both parties in Congress expressed impatience over the failure of the District to bring spending into line with revenue. In April 1995, President Clinton signed into law an act (Public Law 104-8) creating the District of Columbia Financial Responsibility and Management Assistance Authority (commonly referred to as the DC "Control Board" or "Financial Authority"). This board was vested with powers to oversee city spending, including the power to rewrite contracts, terminate personnel, overrule Council legislation, and take over entire departments. In 1996 - 1997, the Control Board assumed oversight of the operations of District schools and police. By mid-1997, as the crisis continued to intensify, the Administration and Congress reached agreement on a rescue package that offered key benefits to the District, including tax breaks, a transfer to the federal government of the multi-billion dollar shortfall in funding District pension liabilities, an increase in the federal share of District Medicaid expenses, and other benefits. The price for this significant federal relief was a transfer of substantial authority over critical city agencies from the Mayor to the Control Board.

This sketch does no justice to a complex story in its own right. Nor are we equipped at the present to describe all of the implications of this history for the design and implementation of the Demonstration. Three principal implications have been suggested to us:

- The crisis created an increasingly powerful outside review board, which created an important avenue of appeal for Demonstration opponents.

- Amidst the mounting fiscal crisis, this Demonstration seemed forward-thinking--more like a part of the solution than a part of the problem. Thus, for example, Mayor Kelly was said to have supported the Demonstration in 1994, in part because she was under pressure to show examples of active management to control city costs, and this was such an example.

- At the same time, the Demonstration deals with such a small part of the overall Medicaid population that it is easy, amidst the crisis, for CHCF and others to have their attention drawn elsewhere. The small CHCF staff has so many issues before it that this Demonstration cannot claim sustained senior management attention--especially because, now that the Demonstration is up and running with few complaints (on which more below), it does not demand attention.

The fiscal and political crisis of the District will not have simple impacts on any important part of the city's business, so it will be important to keep this surrounding, fundamental change in mind, as we continue our analysis of the implementation of the Demonstration.

2.3 The Target Population for the Demonstration

The target population for the Demonstration is "children with special needs"--children who have serious learning disabilities, speech and language disorders, mental retardation, serious emotional disturbances, physical or sensory disabilities, or other special needs. Seriously disabled children are eligible for the federal Supplemental Security Income (SSI) program. Begun in 1972, SSI establishes a cash benefit for poor elderly and disabled persons, using a national income eligibility standard. SSI recipients are categorically eligible for Medicaid in the District, as in most states.[12]

The Demonstration sought to serve children with special needs, not adults, a limitation formally taken into account by limiting enrollment to children and adolescents aged 21 or younger. While all of these children were eligible for Medicaid, children on Medicaid who did not meet the SSI disability guidelines were not eligible. In addition, children who met those guidelines but were dual (Medicare and Medicaid) eligible were not eligible for the Demonstration. Finally, certain restricted Medicaid recipients who met the SSI guidelines were not eligible.[13] Overall, it was expected that the target population for the Demonstration totaled 3,000 children in the District.

We understand from interviews that there was a developing understanding in CHCF in 1993 - 1994 that high cost populations such as children with special needs were an important part of the Medicaid cost problem. However, we are not sure how detailed this understanding actually was, given data limitations faced by an agency with few staff or other resources for analysis. District Medicaid at this time did have a consultant's report encouraging the use of waivers for reform, pointing to five areas in particular, including mental health, special needs, AIDS, and substance abuse. As a policy matter, Medicaid was sympathetic to the conclusions in the consultant's report. But it did not have the dollars or the staff to put together such programs.

As part of our evaluation, we sought data on the expenditure and utilization patterns of this target population. We were unable to obtain any such information. GAO (1996) notes that the District does not track the type or cost of specific services provided through its Medicaid program. District officials did report that the information can be accessed through multiple sources, but GAO concluded that "the data can not be easily converted into a useable form for data analysis." The District's Medicaid Management Information System (MMIS) and HCFA are able to report aggregated data on the District's Medicaid population. However, the data are never specific to SSI-eligible, disabled children.

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[12] Twelve so-called 209(b) states use more restrictive financial criteria to link SSI with Medicaid.

[13] These exclusions from eligibility are described in Agreement between the District of Columbia (CHCF), and Health Services for Children with Special Needs, Inc., dated November 30, 1995 (as amended December 14, 1995), p.25. Restricted recipients are Medicaid recipients deemed to have used services in the past at a frequency or in an amount not medically necessary. These restricted recipients have been restricted for a period of time to obtain Medicaid services from designated providers only.

This does not mean that no such data were available to CHCF decision-makers in 1993 and 1994, when initial commitments were made to develop the Demonstration model. Senior decision makers doubtless had data fragments, at least, that are unavailable to us now. Indeed, in interviews with District staff, we were told that the Commissioner of CHCF in 1993 had gotten some data on where long-term care kids were getting care. (This exploration was done as part of the Commissioner's more general concern to capitate key streams of expenditure.) Projections apparently made at this time showed that 140,000 recipients were costing $850 million. The Commissioner claimed that dollars per beneficiary and dollars per encounter were too high--e.g., lengths of stay were extremely long. The Commissioner reportedly began to think about the idea of "managed care for kids."

If these reports are true, CHCF was in important ways prepared for the managed care proposal soon to come from the Hospital for Sick Children (HSC) in the District. Before considering that proposal and ensuing developments, we will present some background information on HSC and HSCSN.

2.4 The Hospital for Sick Children and HSCSN

For over a century, HSC has been a primary site of care in the city for children with chronic needs and for poor, unwed mothers. As of 1978 (when HSCSN's CEO first joined HSC), HSC was focusing on long-term care for children with non-mental-health disabilities. HSC was the single largest Medicaid provider for this population, before the Demonstration.[14] The reliance was reciprocal: 99% of HSC's patients were Medicaid-funded. In terms of source of patients, approximately 66% were from the District, and 25%-30% from Maryland, with a few percent each from Virginia and private pay sources. HSC also had other programs, including: (1) contracts with District public schools to provide care and instruction for severely compromised students (e.g., students needing to have a doctor or nurse nearby); and (2) some work mainstreaming children who had been deinstitutionalized.

As shown on Figure 2-3, HSC was organized into three major components: the parent company (HSC Corp.), a foundation (to isolate the endowment dollars); and the hospital itself. After the HSC board approved development of what became the Demonstration model, a fourth component was added to the HSC organization: Hospital for Children with Special Needs, Inc., a non-profit corporation. Finally, after the Demonstration had been launched and HSCSN began to explore the sale of services based on its Demonstration experience, a for-profit subsidiary was created under HSCSN. More will be said on these Demonstration-related developments below.

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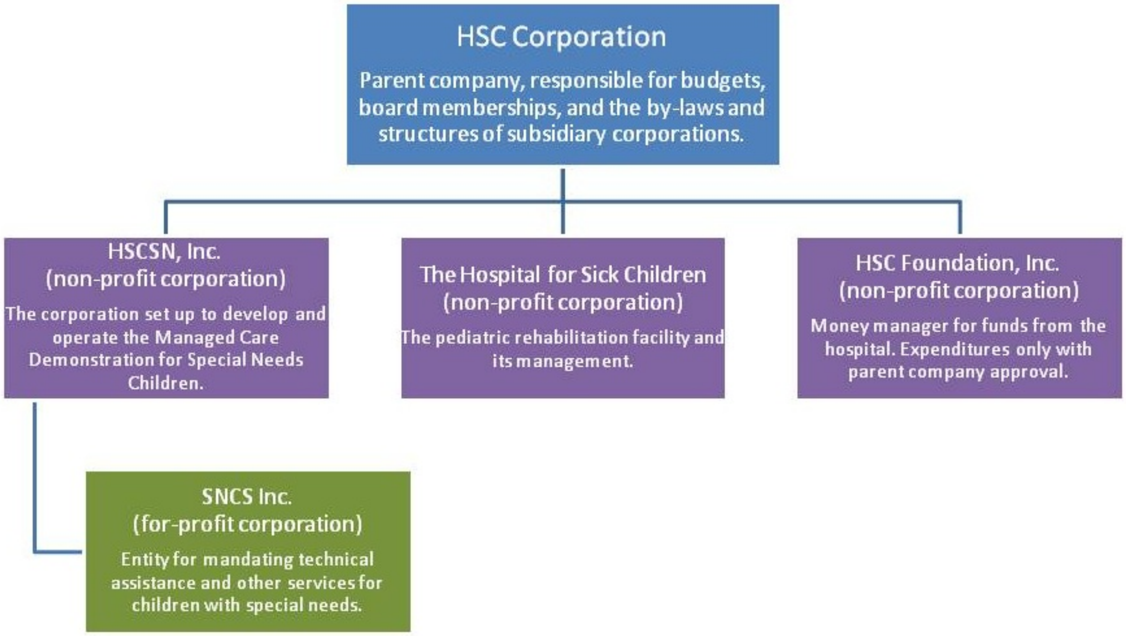
[14] This appraisal of HSC's importance as a provider for this population is based on data analyses done by HSC's consultant for the Demonstration, Lewin-VHI.

FIGURE 2-3. Organization Chart for the Hospital for Sick Children



As the 1990s unfolded, HSC was an old-style hospital, in the narrow sense that its payer base was almost entirely based on fee-for-service arrangements. HSC ran no managed care networks and was not part of any networks of note. HSC was ill-prepared for a new age of managed care and health reform. The board of the company became increasingly concerned about that awkward market position. HSC thus had important strategic interests in the development of managed care capabilities.

2.5 Origins of the Demonstration Proposal

In 1993, HSC completed renovations of its old building and wanted to display the results to its peers. To that end, HSC arranged a meeting of what was then called the National Association of Children's Hospitals and Related Institutions (NACHRI) for May 1993. The topic of the conference followed naturally from the ferment of the day. Specifically, issues of health reform/managed care were under active discussion among all serious health-related audiences, propelled by changes in the health care market, a presidential campaign, the commitments of a new Administration, and other factors. In this changing market, the role of HSC-like hospitals was unclear--apparently, most such hospitals were, like HSC, still operated to fit a fee-for-service world. The conference thus focused on the role of such institutions in a system increasingly dominated by managed care.

While managed care was to be the real substantive focus of the NACHRI meeting, everyone's attention instead was drawn to a small set of first-person talks by parents and children about their experiences with the current system. In those discussions, the hospital stay was "glossed over in a second," according to one HSC participant. To those who had to use the system, the real problems of coordinating care occurred once the patient was discharged, involving such matters as transportation, lining up multiple specialist visits in the same day, and seeing a different physician on each visit so that no doctor was familiar with their case.

After each discussant unexpectedly emphasized this sense of the problem, the idea arose that managed care--viewed as coordination of care, not limitation of care--could really work with this population and save money in the process. At lunch, the idea for a demonstration project was hatched, a project that would look at the problem globally. Who could do it? One of the leaders of the conference from HSC thought that HSC might be able to do it: being in the District, with the U.S. Department of Health and Human Services right there, with a politically prominent board to push the idea, and with resources possibly available to develop the idea, HSC would be well-positioned at least to explore the idea.

By chance, HSC had scheduled an annual retreat of its Board of Directors, immediately to follow the NACHRI meeting. Many of the people on hand for the board meeting had just come from the NACHRI discussions. This chance scheduling gave an impetus to the Demonstration idea. The formal agenda of the board meeting included a number of conventional items. However, a doctor who had been involved in the earlier NACHRI discussions urged the board to ignore the formal agenda and to focus instead on putting together a managed care demonstration for children with special needs.

The board agreed to set up a five-person task force to explore the idea and to report on its feasibility. The task force reported a month later. Its conclusions were as follows:

- a managed-care model for children with special needs could be made to work;
- it would be possible to implement the model under a section 1115 waiver;
- it would be necessary to establish a care management component and a risk component to do the Demonstration, and to engage an insurance company to reinsure the risk; and
- it would be necessary to determine the appropriate organization form for the entity managing the model (e.g., should the entity be established under the hospital? free standing?).

The board approved a major feasibility study. At that point (June 1993), HSC embarked on major design efforts.

2.6 Developing the Waiver Proposal

The cost of putting together an initial feasibility study was borne by HSC. HSC set up a five-person task force composed of four people from HSC and an expert from Lewin. The task force was assisted by an outside facilitator. According to HSC, the task force spent almost nine months (until January 1994) and $250,000 in consultants' fees on the development of the model. Key assistance to the task force was provided by Lewin-VHI and by HSC's attorneys and accountants.

As part of this work, HSC called the Commissioner of CHCF (head of the District Medicaid program) and broached the Demonstration idea to him (circa May-June 1993). District Medicaid at this time had a consultant's report encouraging the use of waivers for reform and, as a policy matter, was looking for ways to capitate streams of expenditure. CHCF was thus sympathetic to the idea that HSC raised. CHCF did not have the dollars or the staff to put together such programs. HSC representatives said they could get the money from HSC's board to do a feasibility study.

This group prepared a report that went to the hospital, parent company, and foundation in January 1994. A day-long board meeting followed and ran into the night. The ultimate conclusion of these deliberations was that development of the model would require $1 million in additional startup funds, plus a $1 million performance guarantee.

Meanwhile, District mayoral elections were to be held in late 1994, and the mayor was fighting a do-nothing image. The District government put the Demonstration proposal on a fast track at this point.

On February 2, 1994, HSC incorporated Health Services for Children with Special Needs, Inc. and began hiring new staff and looking for new offices. A senior HSC manager, who had been the lead person at HSC in the Demonstration development work to this point, resigned from the parent company to become CEO of HSCSN. At around this time, HSCSN rented a fairly large space on Connecticut Avenue NW--expensive space which meant that the HSCSN venture was now a major financial wager.

The only people brought over from the hospital to staff HSCSN were: (1) the senior manager who became the CEO, and (2) three members of the parent board who became the nucleus of HSCSN's seven-person board. Otherwise, HSCSN was entirely staffed by people hired from outside HSC, usually for their knowledge of managed care or their knowledge of the healthcare system. This pattern of hiring suggests concretely the limited managed-care experience of HSC's staff prior to the Demonstration. In April 1994, HSCSN filed with the IRS to obtain not-for-profit status. The IRS approved the application in late May, a relatively rapid approval that HSCSN thought resulted from the intimate connection of the project to Medicaid and the clear purpose of the project to serve a special population.

On March 17, 1994, a formal waiver application was submitted to HCFA. This application described a model based on a number of key decisions. First, the model envisioned that HSCSN would take the fragmented care delivered in the fee-for-service system and--with the incentives of a fixed capitation rate--<u>integrate and manage the care actively</u>, across the full spectrum of covered services and in a fashion sensitive to the particular needs of each child. HSCSN planned to have information systems and a system of care managers in place to perform the actual integration of care. HSCSN was expected to be more flexible and opportunistic than the District government could be in rationalizing dimensions of coverage and care. The Demonstration thus represented a form of privatized administration, using the incentives of capitated funding. In some cases, it was expected that HSCSN's management of care would reduce the care beneficiaries received. But selective increases were expected as well. For example, small physical changes in beneficiaries' homes (e.g., ramps), telephones, and special forms of transportation could resolve critical difficulties for some beneficiaries and actually reduce the costs of service. Such non-standard benefits were extremely difficult to fund under Medicaid, but were expected to be readily funded by HSCSN when those benefits made sense. There was in this model an assumption that the Demonstration system could be more efficient, in that beneficiaries could get improved services and costs could be saved at the same time. There was graphic testimony by parents at the HSC conference in 1993 and in subsequent focus groups to motivate this possibility. But it is also fair to say that the model as such was untested.

Given the general commitment to integration of services, there was also an assumption that the Demonstration model would be effectively spliced into the complex web of public support programs for children with special needs. What this meant in practice was that HSCSN planned to coordinate with other programs and providers at the boundaries of HSCSN's responsibilities--notably, the schools, the mental health system, and the foster care system--to provide a new measure of integration of those services with the Demonstration services. One sign that this hope might be difficult to realize came when the services provided through the District schools were carved out of the capitation rate (see below) and, later, in the apparent difficulties of working with the District schools (see Chapter 3). But the premise of the Demonstration was to improve such linkages, and the proposal to HCFA assumed that such improvements would be pursued.

Second, the model proposed was based on a <u>somewhat accommodating capitation rate, with risk corridors</u>. The proposal asked for 97.5% of the estimated average composite fee-for-service cost, rather than 95% or 90%, in order "to give this a chance to succeed," according to one of the outside consultants. The whole point was not to attempt to garner the largest possible savings right at the start of the Demonstration.

Lewin-VHI did most of the analysis to support the proposed capitation rate. For this purpose, Lewin obtained detailed fee-for-service data from First Health (the Medicaid intermediary for the District). Lewin found that the data on eligibility were "terrible." At this point, Lewin became concerned that the denominators for rate calculations (the number of beneficiaries to whom given aggregates of cost were ascribed) were too large-meaning that the actual costs per beneficiary would be understated.

The key fear was that HSCSN might incur a loss so large that it would bankrupt the organization. HSCSN said that it was willing to forego the opportunity to make big money on the upside, but that it needed some protection against downside risks. In discussions with the District, HSCSN sought to take the "win big, lose big" element out of the model. This effort led to the creation of risk corridors on both sides of the proposed capitation rate. Initially, based on Lewin's work, HSCSN proposed a capitation rate in the range of $1,200 to $1,300 per member per month. This rate included certain very high cost items: transplant cases, services covered in the District Public Schools, and others. The District carved these items out of the rate. After those costs were eliminated, the rate came down below $1,000 (the rate ultimately agreed upon to cover the first year of the Demonstration--a partial year from December 1, 1995, through September 30, 1996--was $997.71). This rate was then to be trended for inflation and the "prior year experience" (after much discussion with HCFA, a 4.6% inflation rate was agreed).[15]

The third major assumption of the model (especially in light of later political controversies) was that the model would be operated under <u>a sole source contract</u>. HSCSN considered a sole source contract as a necessary condition for the work it was doing. In HSCSN's view, the number of children involved was too small for multiple contractors, so there could only be one contractor; and given that HSCSN was funding the development work at its own expense, the one contractor should be HSCSN. The District was in a difficult position to disagree, as it lacked staff and other resources to do the development work itself. No one else was coming forward to volunteer, although to be sure the District did not solicit a lot of community input at this stage (on which, more later). A virtue was made of what may have been a necessity. In most states,"you wouldn't dream" of sole source contracts, as noted by one consultant who worked on the project. But in this city for this small population, an argument could be made to support sole source contracting; and on that basis, the District and HSCSN developed the Demonstration proposal.

The fourth key assumption of the model was that <u>enrollment by members of the eligible population would be mandatory</u>. There are many different possible enrollment designs for a demonstration like this one. Three particular designs proved to be most important for this Demonstration:

- <u>mandatory enrollment</u> in the Demonstration for all beneficiaries.
- <u>default enrollment</u> in the Demonstration--i.e., automatic enrollment in the Demonstration for all beneficiaries who fail to take an affirmative step to enroll in feefor-service.
- <u>voluntary enrollment</u> in the Demonstration--i.e., automatic enrollment in fee-forservice for all beneficiaries who fail to take an affirmative step to enroll in the Demonstration.

The model proposed to HCFA in the waiver application was the first one, mandatory enrollment. Under this model, all special needs beneficiaries were to be

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[15] Details of the financial terms ultimately established are from Agreement between the District of Columbia (CHCF), and Health Services for Children with Special Needs, Inc., dated November 30, 1995, Article 7. the inflation terms are detailed in HCFA, "Health Care Financing Administration Special Terms and Conditions," project no. 11-W-00021/3, dated October 13, 1995.

automatically assigned to the Demonstration. In conjunction with the sole source contract, this decision meant that the health plan would not face a serious marketing burden to persuade beneficiaries to enroll, nor would it face serious risks of selection bias. The latter were not trivial: according to an outside consultant to HSCSN, 5% of the beneficiaries generate roughly two-thirds of the costs, *so it becomes a big issue as to where that 5% of the population ends up*--in one health plan or another, in managed care or fee-for-service. There were thus compelling financial reasons to avoid the vagaries of freer enrollment choice by beneficiaries. From a different point of view, however, mandatory enrollment in a single-source Demonstration also meant that there would be substantial limits on beneficiaries' choice of providers--indeed, disaffected beneficiaries could not even change managed care plans, much less avoid the managed care features of the Demonstration, in the model that the District first proposed to HCFA. This represented a more restrictive set of choices for beneficiaries with special needs and disabilities than the District offered or planned to offer AFDC and other beneficiaries.[16] That distinction was important in subsequent waiver discussions with HCFA (see below), as it appeared to be the kind of differential treatment of populations with special needs that the Americans with Disabilities Act (ADA) prohibited.

In the course of negotiations between HCFA and the District, the mandatory enrollment model later changed to a default model, then to a voluntary model (see section 2.10). This evolution to voluntary enrollment transformed the Demonstration model into a marketing model. This change caused concern among HSCSN and its consultants, since enrollment levels and mixes had not been variables in the projections on which rates and feasibility determinations were based. Those projections assumed a mandatory enrollment model.

2.7 Negotiating the waiver with HCFA

CHCF submitted its waiver application on March 17, 1994. HSCSN apparently expected approval of the waiver to take only four months. (Documents at the time suggest a possible startup of August 1, 1994, or 4-1/2 months after the application was submitted.) In fact, the negotiation process took 19 months from the date of submission to the date the waiver was approved (October 13, 1995),[17] and there were important changes (notably, in the enrollment model) after waiver approval.

HCFA's initial review of the application concluded that the District was proposing an interesting model that nonetheless contained: (1) certain problems (notably, an enrollment model that failed to comply with the ADA); and (2) certain worrisome

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[16] The District was at this time planning an increasingly restrictive set of managed care initiatives for the conventional Medicaid program. However, these plans contained key elements of flexibility and choice--most important, choice among multiple plans--that were not contained in the application for the special needs waiver.

[17] Note that the time from organization of HSCSN to approval of the waiver (February 2, 1994, to October 13, 1995) was 20-1/2 months; the time from waiver application to the formal start date of the Demonstration (March 17, 1994 to December 1, 1995) was 20-1/2 months; and the time from waiver application to approval of the marketing operations for enrollment (March 17, 1994, to December 15, 1995) was 21 months.

exclusions of coverage (notably, of children with AIDS and severe mental illness). HCFA also concluded that the application was not sufficiently developed in a number of important particulars (e.g., the quality assurance system and the provider network). By June 1994, HCFA decided to go forward with further development of the proposed model, after which the terms of the waiver could be discussed if that was warranted. To support that effort, HCFA awarded a development grant to the District in August. Development efforts over the next year appear to have been performed by HSCSN staff, working in support of District project staff.

The delay in the review process made it difficult for HSCSN to continue to get funding from its parent--in the approximate words of an HSCSN manager, "the first time around it wasn't so bad, but the tenth time around, there was real division on the Board of Directors." Delays in approval of the waiver led HSCSN to furlough people, to hold emergency meetings of its board, and to take other measures that were (in HSCSN's view) extraordinary. Members of the parent and sister companies began to get very edgy, claiming that HSCSN was "sucking up the funds of the company," according to one HSCSN senior manager. There apparently were some resignations, firings, and fights.

According to at least one outside consultant to HSCSN, the review process would have been sufficient to derail the Demonstration, if the project had not had so much momentum. In his approximate words, "somewhere along the way a line was crossed-people installed, dollars spent--and it became [the HSCSN CEO's] mission in life to make it succeed. That, probably more than anything else, sustained them [HSC/HSCSN] through the delay."

Perhaps the key question to ask about this process is whether the frustrations were more a product of misaligned expectations (on the part of HSC, HSCSN, and the District) or 1115 review and decision making processes. Two points are worth noting:

- The key players in the waiver review process--principally, HCFA/ORD, CHCF, and HSCSN--were unfamiliar with each other. This is not unusual for local demonstrations operating under waivers approved by HCFA. However, it increases the potential for misunderstandings and unexpected delays, which were an important factor here.

- HSCSN's estimated time to startup after submitting a waiver application--4-1/2 months--was not very realistic, based on the issues at stake and the typical times required for HCFA to review such applications. While there were public discussions at this time about accelerating HCFA's review process, the process had not been accelerated. The approval process commonly requires 9 months or more to complete a review and reach a decision regarding approval. Meanwhile, the District and HSCSN may have underestimated an important distinction: they were no longer in the "waiver review period" at the time HCFA awarded the development grant. This latter decision was a move back to the drawing board, with important implications for the timeline of the project.

The progress of these discussions was complicated by the lobbying activities of project opponents. That opposition is reviewed in the next section below.

2.8 Political Opposition

HSCSN's application for a waiver met with opposition from a group known as "Responsible Parents Against DC Medicaid." The group consisted of day treatment centers and other service organizations that provided care to the District's Medicaid population. This group (hereinafter, the "Opposition") was comprised of the following organizations:

- Large day treatment centers (PSI, National Children's Center, and St. John's Community Center)
- Smaller day treatment centers (Lt. Joseph P. Kennedy Institute and the Easter Seals Society for Disabled Children)
- Service organizations (United Cerebral Palsy of Washington and N.Virginia and D.C. Association of Retarded Citizens (ARC)).

The leader of the Opposition (according to various documents from HSCSN) was the Executive Director of St. Johns Community Center, who was also President of the DC Coalition for Community Services. The Coalition exists to foster communication among service organizations providing care to persons with disabilities in the District. From our understanding, the Coalition was also a channel for some of the day treatment centers to draw the support of others not as directly affected by the Demonstration, such as DC ARC. Despite the more public presence of the President of the Coalition, the organized lobby was funded by the largest of the day treatment centers, PSI. The Opposition was extremely frustrating for HSCSN and the District.

Documents given to us by HSCSN and conversations with representatives from the Opposition suggest that criticism of the waiver began shortly after HSCSN's submission of its application on March 17, 1994, and lasted beyond the approval of the waiver. A chronology of events given to us by HSCSN indicates that conflicts regarding the waiver were aired to various HCFA officials, including the Administrator; Members of the Council of the District of Columbia (Committee on Human Services); the Commissioner of CHCF; the Mayor, and the D.C. Control Board. These officials and agencies were contacted by the Opposition through written correspondence as well as personal visits.

According to the President of the Coalition, opposition to the Demonstration began when day treatment centers were first approached by representatives of HSCSN and invited to join the network. The message communicated to the treatment centers was "you have to sign up with us as a provider or you'll be out of business." St. John's and day treatment centers with early intervention programs were said to be ready to collaborate with the plan, but took umbrage at the attitude of HSCSN's representatives.[18] The Coalition President thus contacted HSCSN's CEO to report the behavior of the HSCSN staff, suggesting that HSCSN invite the day treatment centers as well as other members of the DC Coalition for Community Services to meet and discuss the intentions of the Demonstration.

The meeting was sponsored by HSCSN, but members of the Coalition were invited to participate. It is not clear when this meeting occurred; however, the first documented letter written by the Opposition was in July 1994, which would suggest that the meeting occurred prior to that date. In this letter, HSCSN's CEO explained that the Demonstration called for mandatory enrollment for SSI-eligible disabled children into HSCSN. Then, according to the President of the Coalition, the CEO repeated the message of "join or sink." From what we have learned, the gathering appears to have provoked hostility from those invited and made them feel vulnerable. Soon afterwards, participants in the initial meeting secured a copy of HSCSN's original waiver application and began to organize.

As summarized in documents and in interviews with members of the Opposition, criticisms of the proposed Demonstration centered on the following:

- **Lack of specific contractual plans given to providers.** The Opposition's letter to ORD on July 24, 1994, indicates that the contracts given to providers by HSCSN did not "define or describe" the services that would be covered by the plan in the future and also did not provide any assurance of the number of clients to be referred.

- **Misrepresentation.** According to our interviews, the original waiver application listed some of the members in the Opposition as having endorsed HSCSN's proposal. The members listed had no prior knowledge of HSCSN's existence before being approached by its representatives. Opposition letters to HCFA at the time raise the charge of misrepresentation.

- **Absence of evidence for the need or effect of the Demonstration.** In a letter to the HCFA Administrator on May 26, 1995, the Opposition lists several deficiencies in the District's decision to support the waiver. There was no analysis of the need for this type of waiver other than the District's desire to reduce spending on the existing delivery system. The document asserts that "there had been no research conducted to determine whether there is a current lack of systems or duplication of services." The same letter also indicates that there had been no evidence of the waiver's future financial savings or a research design that would evaluate the effectiveness of the Demonstration.

- **Sole-sourcing.** The lack of a competitive bid suggested to leaders of the Opposition that the waiver was "another DC deal." Documents written by the

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[18] Of course, it is difficult to separate what might be the centers' legitimate anger from other sources for their opposition: notably, their self-interest, as new controls from managed care threatened to change traditional levels of discretion and oversight.

Opposition state that "the Commission [DC CHCF] is moving forward with a plan which we believe will violate District law by rewarding [sic] a $100 million sole source contract to a newly created agency with no organizational history in managed care to implement the waiver." The only assurance that the Opposition was given as to the fairness of the procedure was that the "Mayor had written a letter to the federal government" expressing that the waiver was "in the best interest" of the city.

- **Mandatory enrollment.** Opposition letters written to members of the DC Council reveal that there was concern that CHCF's support of mandatory enrollment would result in parents' loss of "federal guarantees of freedom of choice."

- **Lack of community involvement in the design of the Demonstration.** The Opposition focused on the lack of provider input in the development of the Demonstration. A letter to the HCFA Administrator asserts that "All providers were not invited to this forum (May 16, 1995)." The letter goes on to mention that "key players in the provider community including the directors of several major contracted providers and the president of DC Coalition for Community Services" were not invited to HSCSN's forum. However, according to interviews, the Opposition also believed that stakeholders in the Demonstration such as the parents of the children, service organizations, and advocacy groups should have been invited to participate in the development of the Demonstration.

The Opposition was described by HSCSN as being animated solely by self-interest. It was apparent to HSCSN that the providers in the Opposition had financial reasons to be afraid of the waiver. The day treatment centers are paid approximately $100 - $140 per day for each slot filled. Given the school calendar, each day treatment slot filled means an average of 20 days per month at these rates, for nine months of the year. Moreover, the Demonstration threatened to control the day treatment centers in new ways. Ordinarily, the centers had substantial discretion over the services to be provided to each child on site. Under the Demonstration, the centers' decisions were to be subject to the rights of care management and referral of HSCSN. In a letter dated August 25, 1997, to the D.C. Council's Committee on Human Services, HSCSN referred to the Opposition as being "providers afraid of the impact that managed care will have on their financial well-being. They have no experience in a competitive managed care environment and would rather oppose change, however inevitable, than embrace competition." Indeed, HSCSN found much that the Opposition did to be a transparent facade for selfish interests--e.g., the attempt by the Opposition to represent itself as if it were a disinterested representative of the interests of children with special needs and their families.

Although they considered the Opposition's claims to be without merit, HSCSN and the District felt compelled to respond. HSCSN countered by pointing to the support of the District government and provider community for the Demonstration, the reputation of HSCSN's staff, and HSCSN's resolve to work in the best interests of the children. In a letter to the HCFA Administrator (June 9, 1995), HSCSN referred to its 2-year collaboration with the District to develop a sound plan that might achieve cost-savings of over $3.5 million. In addition, HSCSN assured HCFA it would work to support EPSDT services and coordinated care for all members. In this letter and others, HSCSN acknowledged its position as a newcomer to the District's health care delivery system, but points to its association with the Hospital for Sick Children, whose reputation of caring for individuals with disabilities is over a century old.

HSCSN and the District continued to address complaints in meetings after the waiver was awarded. Both the District and HSCSN believe that the parents were manipulated by the Opposition to prejudge the Demonstration. However, the District concedes that, in terms of community consultation, the District could have done more earlier--in particular, to involve parents. According to the District, by the time HSCSN and CHCF had their first public forum for families on July 17, 1995, they faced a fairly hostile group of parents who (HSCSN believed) had been misinformed of HSCSN's plans. The District followed up on all the problems raised at the meeting and offered the parents individualized meetings and volunteer opportunities to serve on various committees. From then on, the District began to meet with parents at schools and with advocacy groups. The District also now realizes that, instead of trying directly to market the plan to the families, they should have hired a community-based organization or child advocate to help them.

The political opposition had an effect on HCFA and within the District. For example, the D.C. Control Board, which had originally said it would not look at this contract, changed its mind after the waiver was granted, apparently because of the continuing claims of the Opposition. The Opposition believes that its efforts played a major role in HCFA's refusal to approve mandatory enrollment, and also led to the increased involvement of the community later in the waiver process. The former conclusion is likely wrong, since HCFA found conflicts between mandatory enrollment and the ADA when the District's application was first received. In any event, as an HSCSN manager noted to us, the change in the enrollment process that the Opposition sought eventually served to provide political cover to the Demonstration--especially in discussions with the Control Board-since beneficiaries had an opportunity to decline the Demonstration. The President of the Opposition agreed that the Opposition's effort waned after enrollment became voluntary. In his words, "The rest was about egos."

Now that the Demonstration is up and running, there has been little resistance to the Demonstration from the former Opposition. In fact, all of the day treatment centers are now providers in HSCSN's network (the last center, PSI, joined in late 1997). Members of the Opposition claim that they now approve of HSCSN's care management system and encourage eligible parents to join HSCSN.

2.9 Community Involvement

According to everyone we interviewed--employees of local advocacy groups, providers of support and educational services to children with special needs, officials of the District, and staff at HSCSN--members of the community were not involved in the planning and design of the Demonstration at the outset. As noted earlier, this lack of involvement caused resentment in some organizations, especially when the Opposition sought to mobilize people against the planned initiative. Representatives from organizations that wanted to be involved claim that they did not receive formal notification about the Demonstration until the bulk of the negotiations between HCFA, the District, and the Hospital for Sick Children were well underway.

Some respondents to whom we spoke observed that the planners became more receptive after they received feedback during the public hearing. The opponents' ultimate goal was to have the entire plan revised, with input at every stage from the community. However, they were satisfied when the enrollment process allowed families to decline the Demonstration and planners provided more details on how the Demonstration would deliver services to children.

Apparently, after the public hearing, and perhaps in response to the suspicions that the opponents had raised regarding the Demonstration, HSCSN marketing staff made a concerted effort to inform the provider and advocacy groups in the community and enlist their support. They made presentations about the program at meetings held by coalitions of advocacy and provider organizations serving children with special health needs. They also convened several town meetings and sponsored a conference with the same goal of informing the community about the program. According to some of the respondents who were present at these meetings, HSCSN presented itself as an organization that was willing to collaborate with community groups to provide comprehensive care to children with special health needs. HSCSN representatives addressed concerns about managed care and whether and how the program would provide educational and other support services that children with special needs and their families often require. The presentations were apparently successful in garnering the support of organizations that had not heard of the Demonstration and in changing the opinions of some that were formerly opposed to it. However, organizations were not invited to join in the planning and design of the program. As stated earlier, this omission was a problem for some of these organizations. But other organizations were content not to be involved, once they knew that the Demonstration would not pose a threat to their clientele and would actually work collaboratively with them and assist them in service coordination.

Respondents both in the key informant interviews conducted for the community involvement study and in the parent focus group study indicate that parents were not involved to any significant degree in the planning of the Demonstration. However, unlike the organizations which were opposed, it appears that in general parents were not upset by their non-involvement. This may be due to the enormous stresses and the burden of caregiving responsibilities faced by many of these parents, leaving them limited time, if any, to be involved in community activities.

However, we also collected some data from parent focus groups that suggested the opposite conclusion. In particular, we talked with a group of parents who declined to enroll their children in HSCSN because they had negative perceptions of managed care and/or negative experiences with it. Many of these parents objected to the Demonstration and felt that the District was trying to coerce parents to enroll their children in HSCSN. A few expressed the view that they might have been persuaded to enroll their children in the program had they been informed about the Demonstration and been involved earlier in its planning and design.

2.10 Approval of the Waiver and the Startup of the Demonstration

As the waiver review process continued in 1995, key details of the project were revised. Perhaps the most important set of issues concerned the design of the enrollment process. The design of the enrollment process went through at least three major phases and got caught up in more general discussions between HCFA and the District over implementation requirements for the Demonstration.

Phase 1: mandatory enrollment, as proposed in the original waiver application. As noted, the original waiver application proposed mandatory enrollment. Each month, the District would add one-sixth of the eligibility rolls to the managed care enrollment, and begin paying for them immediately. Beneficiaries would have the ability to opt out within 30 days, but after that would be locked-in for 6 months, except for cause. At that point, beneficiaries could opt out for any reason.

Phase 2: default managed care enrollment, as approved by HCFA in the agreement on terms and conditions for the waiver. HCFA's final approval of the waiver on October 13, 1995, changed the original mandatory enrollment design to a default design. Under the default design, beneficiaries would be notified of their ability to opt out of the Demonstration to fee-for-service if they chose. But if they failed to exercise that choice within 45 days, they would be enrolled in the Demonstration by default.

Those who *chose* Demonstration enrollment were to be locked in for 6 months, during which time they could shift to fee-for-service only for "good cause" and after which they could shift for any reason whatsoever (Waiver, 10/13/95, p. 2). Those who *defaulted* into the Demonstration were to be able to switch for any reason for 45 days, for good cause through the 6-month window (inclusive of the 45 days), and thereafter for any reason. Those who chose fee-for-service were to be able to enroll in the Demonstration at any time, with a 6-month lock-in to follow, except for good cause.

There were two principal reasons HCFA insisted on this change from mandatory to default enrollment. First, the ADA contains provisions designed to prevent funneling individuals with disabilities into a more restricted set of choices than others face-individuals with disabilities have to be given the same scope of choice as others. The District's application, however, proposed to channel all beneficiaries into a single contractor, which represented a far more restrictive set of choices than faced by other Medicaid beneficiaries. Opportunities for Demonstration enrollees subsequently to disenroll did not cure that problem. For HCFA, this differential treatment could not be justified in any terms that would satisfy the statute. Second, there were reasons specifically to worry about this differential treatment, independent of ADA. HSCSN was an entirely new organization and had never delivered or managed any care. HSC was a respected local institution, but HSC had no experience as an HMO or care manager. Forcing all beneficiaries to enroll in the Demonstration was thus a large risk for an indigent, particularly vulnerable population. (It did not help that certain parts of the application that might have provided some reassurance--such as the QA process and the provider network--were considered inadequate by HCFA.)

In view of these reservations, HCFA insisted that default enrollment provisions be changed. HCFA was willing to agree to default enrollment, so long as there were liberal disenrollment provisions for those individuals who defaulted into the Demonstration. These concerns were satisfied by permitting default enrollees to disenroll for any reason whatsoever in the first 45 days of enrollment.

Phase 3: enrollment as implemented--default Fee-For-Service, enrollment into the Demonstration only with explicit choice and in-home assessment. After the waiver was approved, the District signed an agreement with HSCSN on November 30, 1995, that embodied the HCFA terms and conditions for enrollment (i.e., default enrollment to the Demonstration, as described above). However, these provisions underwent important changes immediately thereafter.

Specifically, on or around November 30, as the District was about to send out the first wave of announcement letters to eligible beneficiaries, HCFA informed the District that it could not proceed. The problem here was fairly basic. Under the terms and conditions of the waiver HCFA granted, the District was required to submit a series of items to HCFA for review and approval before Demonstration operations could begin, including:

- a pre-implementation workplan

- an operational protocol, including provisions for:
  - clinical management system
  - proposed service delivery network
  - marketing and outreach strategy
  - enrollment and disenrollment procedures
  - arrangements for the provision of emergency and urgently needed care
  - QA plan, identifying quality monitoring criteria, practice guidelines, and MIS support for quality monitoring

        - provision of encounter data and minimum dataset
        - documentation requirements and audit trails
        - financial reporting requirements

    - the contract between the District and HSCSN

    - the design for a study of utilization, cost, and quality, including baseline data collection plan

    - all notification, informational, or marketing materials to be used to notify and enroll beneficiaries.

By the end of November, none of these items had been submitted to HCFA or approved by it. The imminent release of the marketing package brought to a head the more general failure of the District to submit the required materials and obtain the required approvals. Failure to obtain those approvals meant that important ambiguities in approved terms and conditions--in this case, concerning the enrollment process--had not been worked out. Those ambiguities were worked out in early December, with important implications for how clients were enrolled.

HCFA had a number of minor issues with the marketing package, but the most important issue concerned what steps were required to enroll beneficiaries. The waiver (Section II.3) required the District: (1) to verify that default enrollees had received "eligibility notification" (i.e., notification of enrollment alternatives), (2) to obtain HCFA approval of all materials used for eligibility notification, and (3) to report such verification to HCFA in the course of the Demonstration. The discussions in early December between HCFA and the District served to spell out how that verification was to take place. In a policy decision, HCFA insisted that beneficiaries had to sign a selection form that displayed Demonstration and fee-for-service alternatives and recorded each enrollee's choice to enroll in the Demonstration. HCFA did not insist that this signature was a precondition for enrollment (such insistence would have eliminated the default provision of the waiver). For default enrollees, the signature could be obtained at the needs assessment that was to be conducted shortly after enrollment.

On its part, the District had always required a face-to-face needs assessment by HSCSN. When HCFA insisted that the District obtain a signed selection form from default enrollees (rather than a telephone confirmation with signed followup), the District moved the needs assessment back in the process, making the needs assessment the trigger for enrollment. The District's logic was that the differences between default and voluntary enrollment had been blurred. Enrollees were now required to exercise an affirmative choice, in writing, soon after enrollment; otherwise they would revert to fee-for-service. This requirement was only slightly different from requiring an affirmative choice, in writing, before enrollment. From this point of view, moving the needs assessment back in the process (to occur before enrollment) and making that assessment the trigger for enrollment was not a fundamental change. Meanwhile, the District saw sound policy reasons for making this change. Given the health plan's direct contact before enrollment, the chances for "strong arming" by the plan--as might occur in purely marketing contacts-increased. The needs assessment was designed to give beneficiaries a last chance to say no. Three contacts were now required with each beneficiary before enrollment in the Demonstration: a mail contact, an outreach contact by phone, and a face-to-face needs assessment/signing of the selection form.

Whatever the justifications, the effect of these changes was to transform the enrollment design from default Demonstration enrollment (as provided in the waiver) into default fee-for-service enrollment. The enrollment process now would proceed as follows:

- The District would identify 1/6 of the Eligible Population each month and send out information/enrollment packets by the 15th of the month. These packets would advise the family that they could either keep fee-for-service coverage or enroll in HSCSN.

- The District would send a reminder by mail on the 30th day to all non-respondents.

- *Families that responded to the mailing*--Some families would submit the selection form to the District after the mailing. The District, in turn, would generate a list of these respondents and forward it to HSCSN. HSCSN would then schedule the children of these families for a needs assessment. After the assessment, these children would be deemed formally enrolled. HSCSN would be reimbursed for their care, starting the first day of the month in which their enrollment commenced (which could be the following month or the month after that).

- *Families that did not respond to the mailing after 45 days*--For families that failed to exercise their choice, HSCSN was permitted to market directly to them after the 45th day from the original mailing:
  - HSCSN would contact them personally (in a home visit, preceded if possible by a phone call) to obtain their affirmative decision to enroll in the managed care program. This outreach contact would then be followed by a second in-home contact to perform the needs assessment.
  - At the completion of the needs assessment, those who had said yes would sign the selection form and be formally enrolled. HSCSN would be reimbursed for covering their care, starting the first day of the month in which their enrollment commenced.

- Families that initially chose to keep their eligible child in the fee-for-service program could enroll in HSCSN at any time. After a needs assessment, the children of these families would be formally enrolled. HSCSN would be reimbursed for covering their care, starting the first day of the month in which their enrollment commenced.

- *Payment* for children would be prospective for each month of coverage. The District would provide HSCSN with a final enrollment list by the 20th day of the month. The list would include all children enrolled by the last day of the prior month.

Thus, an enrollment process that was to have expedited inclusion and the growth of the Demonstration census was rearranged to require explicit consent and multiple opportunities to say no. One implication of this change was that--in ways not fully appreciated in 1995--it raised the stakes on being able to contact beneficiaries. Due to systems weaknesses, the failure of most beneficiaries to respond to the initial mailings, and other difficulties, the nominally straightforward task of contacting beneficiaries became more complex and costly. Indeed, in some ways, the outreach process became the most important administrative challenge of the first months of the Demonstration. One implication of this challenge was that it would be more difficult than expected to enroll beneficiaries in the Demonstration--the process would be more costly, and the Demonstration census would grow more slowly than originally expected.

There were also other implications in the shift to voluntary enrollment. The District had said from the start that it did not want HSCSN to make the initial contact with beneficiaries. The District wanted to play the role of a third-party broker, not because this particular organization (HSCSN) would abuse these contacts, but as a matter of sound policy, based on national experience, that it is not a good idea to put managed care plans in the position of making initial marketing contacts. However, the final enrollment procedure--while costly in other respects to HSCSN--actually gives the plan added opportunities to screen and avoid hard cases (given the chances for observation and influence provided by face-to-face encounters in the outreach contacts and needs assessments). It appears that HSCSN would have been happy with what was described as a more typical situation: an enrollment broker, with default enrollment to the Demonstration. But what it had instead was an enrollment broker and a requirement for face-to-face outreach to (as it turned out) almost all of its potential enrollees.

In implementing the voluntary system, there were a number of operational issues on which HCFA and the District disagreed. For example, the District wanted a 30-day waiting period after the initial mailing, before HSCSN could market directly to beneficiaries. The 30-day period was consistent with the 30-day default period being used in the AFDC program (in the latter, beneficiaries were turned over to the managed care health plan after 30 days, if they did not express a choice). HCFA wanted 45 days, however--a requirement that meant that the District had to establish a separate subsystem for the Demonstration (i.e., to reprogram the MMIS). HCFA argued that a 30-day period did not leave families enough time to make a considered choice or to investigate the consequences.[19]

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[19] With a 30-day period, beneficiaries' families would have only three weeks to investigate the issues, since it would take a week to receive the materials and send a response.

2.11 Conclusion: Implications of the Origins and Startup of the Demonstration for Other States

It is too soon to draw firm conclusions from the origins and startup of the Managed Care Demonstration for Special Needs Children. But pending further results from the evaluation, as described in the next section, we can at least offer the following tentative implications for other states considering this kind of model:

- At least one mild suggestion is obvious: waiver applicants should not make unrealistic assumptions about the amount of time required to review and make decisions regarding waiver proposals and reach agreement. The assumptions made by HSCSN in this Demonstration bore little relation to the amount of time typically required for such approvals. Conservative scheduling is probably wise.

- That conservatism is especially important when the review process must resolve some fairly substantial issues, issues that in this case were evident almost as soon as the application was submitted. The original design proposed in this Demonstration contained unusual restrictions on beneficiary choice: mandatory enrollment in a single health plan that, although related to a substantial health provider for this population, had no experience doing what it proposed. These restrictions were for care of a notably vulnerable indigent population with substantial service needs. This proposal posed a particularly difficult form of the restriction, especially in view of ADA requirements. That difficulty was reflected in the complexity of the discussions that followed.

- This Demonstration faced political and community opposition that could have been reduced if the District and HSCSN had followed fairly rudimentary forms of consultation. The District now concedes that it should have done more, earlier, to consult the community--and parents, in particular. As it was, parents were uninformed, and that made them more vulnerable to persuasion by others and naturally worried about rumors (some rumors apparently orchestrated by providers) concerning the new Demonstration. Many parents who were opponents later became proponents (two now sit on HSCSN's board), but only after extended efforts by HSCSN and the District to explain the Demonstration. That the parents could be persuaded suggested how useful it would have been to involve them up front. For obvious reasons, HCFA paid close attention to parents' complaints--and to some degree at least, those complaints could have been derailed by earlier contact with parents, in the opinion of District Demonstration staff.

We will expand on these tentative conclusions as our evaluation gathers information from other sources and the implications of early decisions in the Demonstration become better understood.

2.12 Further Research

Our work on the context and origins of the Demonstration is substantially done. However, as the Demonstration proceeds and our evaluation expands, unexpected aspects of the environment will take on additional importance, and the evaluation must be alert to collect data intensively in these areas. Thus, for example, utilization patterns may exhibit pre/post variations that make an understanding of pre-Demonstration patterns more important to document; or difficulties in collaborating with potential partners (e.g. the schools) may increase the importance of understanding the early decisions made by the CHCF, HSCSN, and the District schools. We will do data collection as needed on these issues.

More generally, however, the focus of our future work will be not on the origins and context of the Demonstration, but rather on its implementation. The next chapters begin our discussion of implementation issues.

3. WHAT IS “THE DEMONSTRATION”? SPECIFYING THE INTERVENTION

3.0 Introduction

Managed care systems can be implemented in many different ways, particularly where, as here, the venture is without extensive precedents or long-established protocols. To understand the Managed Care Demonstration for Special Needs Children (the "Demonstration") and its effects, it is obviously essential to establish precisely what the Demonstration interventions are and are not, as actually implemented. The Demonstration plans are clear enough, but many different versions of the Demonstration could follow from those plans. We need to map the interventions with care, to establish a foundation for our implementation analyses as well as to document processes of the Demonstration to support inferences and interpretations of other data (e.g., survey results and utilization analyses).

Having said how important it is to specify the intervention precisely, we have to concede the difficulty in doing so. The key standard against which this information must be compared is a difficult one to establish: what would have happened in the non-Demonstration fee-for-service system, as refined over this same period of time. This counter factual is impossible to establish with rigor. However, we can use interviews and available treatment records to establish characteristic ways in which the process is *thought to* differ from fee-for-service treatment, by the participants in that process. No single source of information or analysis will be able conclusively to establish the distinctive aspects of service provision in the Demonstration. The important point will be to establish whether the many different analyses and vantage points that our evaluation will provide tell a fairly consistent story.

In this chapter, we provide a summary of what the Demonstration intervention is, based on documentation collected to date. Our discussion is divided into eight sections:

- Risk sharing and the concept of managed care for care management
- Changes in the benefit package under the Demonstration
- The organizational structure, staffing, and systems at HSCSN
- Relations of HSCSN with HCFA, District Medicaid, and the community
- Relationships of HSCSN coverage to other service systems, including schools and foster care
- Financial results to date
- Implications of findings to date
- Future research and critical outcomes

The ultimate implication of this discussion is that HSCSN does indeed appear to be managing care in the ways anticipated at the outset of the Demonstration, with reasonable financial results to date, with useful but incomplete coordination with other service systems, and with improved relationships with providers and the community. HSCSN's objectives in the Demonstration are complex, however, and an important question looking ahead is how much of the future activity of HSCSN is directed to the Demonstration and how much is directed to Demonstration-like technologies as a new line of business for expansion outside of the District.

3.1 Risk Sharing and the Concept of Managed Care for Special Needs Children

As noted in Chapter 2, the model for this Demonstration assumed that a private provider, operating under the incentive of a fixed capitation rate and empowered to manage and integrate the care of enrollees, could make care more efficient and increase the quality of care for beneficiaries who--as vividly described in the NACHRI meeting in 1993--face serious difficulties using Medicaid and other services. The point here is not that Medicaid and other services (e.g., public health, schools, foster care, and mental health) are deficient in what they cover, although for other purposes that may be true. The point is, instead, that an extensive array of services is fragmented in the fee-for-service system, and that (prior to the Demonstration) there were no real managed care alternatives to integrate and coordinate the various pieces. The Demonstration brought two new assumptions to that setting:

- **The responsibility to manage care:** While Medicaid and other systems imposed limits on utilization and coverage in various ways (e.g., prior authorization requirements), no one in those systems was responsible for the active management of individual cases--e.g., to assist in scheduling appointments and arranging transportation, to coordinate different treatments, to eliminate critical barriers to care (such as physical impediments in housing), and to refine and adapt overall programs of treatment. The Demonstration proposed to empower care managers to play this active integrating, coordinating role in the care of those beneficiaries enrolled in the Demonstration. These care managers were to be organized into multi-disciplinary treatment teams (MDTs) at HSCSN. The key challenge to these teams was to augment services in cost-effective ways (see below), in comparison to the fee-for-service Medicaid system, to integrate health and social support systems into the managed care system, to establish linkages across different types of Demonstration and non-Demonstration services, and to facilitate access where key barriers to care impeded cost-effective use of preventive and other services.

- **The incentive and capacity to manage care:** Even if the Medicaid program had been given responsibilities actively to facilitate cost-effective, medically necessary care, there were questions about the incentive and capacity of any public agency (and especially of CHCF, in this political context, at this particular time of staff shortages and fiscal stringency) to do so. Indeed, under fee-for-service reimbursement, there were questions about the incentive of *private* agencies to do such management. The Demonstration embodied one particular response to those questions, as it represented a vision of privatized administration, using a contract with a private provider to *internalize the costs and benefits of care management* in a way that was not possible under fee-for-service or public administration. The expectation was that this contract arrangement would create incentives for the active performance of care oversight and management. The encumbrances of a public agency (e.g., constraints on pay, hiring, and firing, and some of the political constraints) could be mitigated or avoided. At the same time, one of the key incentive problems of fee-for-service medicine--i.e., that providers have few incentives to take responsibility for more than their own individual pieces of a child's overall care-could be remedied.

As noted in Section 3.5 below, the actual structure of risk for the Demonstration buffers HSCSN from large losses but also discounts large gains. This risk structure may have complicated effects in practice--certainly, more complicated effects than reflected in the abstract, undifferentiated idea that the contractor has the "incentive to manage care." The evaluation will attempt to clarify what these actual effects are. Suffice it to say here, however, that the basic premises of the Demonstration emphasized that the contractor would be animated to manage care actively, in a way that no public agency or fee-for-service provider would be able to do. Given these differences, HSCSN was expected to be more flexible and opportunistic than the Medicaid program and providers could be, in rationalizing coverage and care and smoothing the difficulties beneficiaries faced in navigating the system.

3.2 The Benefit Package

The composition and administration of the benefit package is a central part of this Demonstration. There are at least three reasons, beyond the purely descriptive. First, when a public or other program capitates its payments to providers, there obviously must be explicit agreement on the minimum benefits the provider is obligated to offer for the fixed, prospective payment. Second, when enrollment is voluntary as here, it is further critical to consider what marketing advantages the benefits of the Demonstration actually confer. Finally, for any sophisticated managed care organization, the most desirable package of benefits is not likely to be the most limited list of benefits, even from a narrow financial point of view. More expansive benefits for preventive care and coverage of more comprehensive tests and other methods of early detection can provide important ways to save money, quite apart from any improvements that result in patient care. In fact, when added coverage is seen to be cost effective, it is reasonable for the provider to offer such coverage, independent of any obligation.[20]

3.2.1 Demonstration Enhancements of Medicaid's Fee-for-Service Benefit Package

In this Demonstration, HSCSN was required to provide the full panoply of mandatory and optional Medicaid benefits available in the District, including inpatient hospital, nursing facility, intermediate care facility, outpatient, physician, family planning, dental, prescription drug, home health, vision care, transportation, mental health/substance abuse, hospice, and other services.[21] In addition, certain special services were explicitly offered under this Demonstration to members of HSCSN:

- **Care management:** Perhaps the defining characteristic of this Demonstration is care management. It includes:
  - 24-hour care management services while enrolled
  - Development and maintenance of individualized plans of treatment
  - Assistance in arranging "...medically necessary services including transportation, medical appointments, and all other covered services"[22]

  In some respects, care management is no benefit at all, but rather a requirement--i.e., something *limiting* care that is a cost to beneficiaries, rather than a benefit. However, the premises of the Demonstration are that this is the most important benefit of all, since it is the part of the Demonstration that most directly addresses the frustration of parents of children with special needs, as expressed in the NACHRI meeting in 1993 and subsequent discussions. It is an empirical question whether care management in practice is doing more to limit care than to provide enhanced and coordinated services.

- **Services provided with prior HSCSN authorization:** The provision of the following services could not be taken for granted. But these services were explicitly listed in the Evidence of Coverage because the provider sought to make them far more available than under Medicaid:

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[20] For an example of a managed care plan offering additional benefits beyond the specified minimum--in this case, in a Medicaid-like managed care plan for children in public schools--see Robert F. Coulam, Carol V. Irvin, et al., "Managed Access: Extending Medicaid to Children Through School-Based HMO Coverage," *Health Care Financing Review*, 18:3 (Spring 1997), 149-175. Of course, this point should not be pushed too far: managed care plans do not reliably have incentives to offer all of the different kinds of care that the payer considers essential. As noted in the text, there must be a specification of benefits that the plan is required at a minimum to cover. But given a specification of minimum benefits, smart plans will find some additional benefits that are cost-effective to provide.

[21] The discussion of benefits in this paragraph is based on the "Evidence of Coverage," Attachment to the Agreement between the District of Columbia (CHCF), and Health Services for Children with Special Needs, Inc., dated November 30, 1995; and interviews with HSCSN and District staff, to clarify the administration of these benefits.

[22] Ibid, Section II.1.

- <u>Limited-use telephones</u>: These are telephones that are blocked for out-of-area calls and have coverage for only a limited volume of local calls. It is difficult to manage the care for a family that does not have a phone, even as it is difficult for such a family to do some proactive things for itself (e.g., arranging at least some appointments, calling for results, etc.). Medicaid did not cover these phones at all, while HSCSN viewed them as essential. (According to interview data, 40-50 current enrollees have such phones, or 2%-3% of all current enrollees.) Although we have no independent data on beneficiary needs, we have the impression that phone installations have been done as a matter of course. If that is so, local-use phones are one small, concise example of how and why the philosophy of this Demonstration differs from conventional Medicaid coverage.

- <u>Home modifications/adaptations as necessary</u>: Just as the absence of telephones can be a barrier to access and an impediment to coordinating care, so too, in a more direct physical sense, can physical barriers or arrangements in homes. HSCSN did not propose to remodel homes simply for convenience, but rather to address serious impediments that were having effects on access to care.

- <u>Feeding programs</u>: By sending a nurse to a home to feed a special needs child, HSCSN could free the parent for work and other support activities.

- <u>Respite care</u>: In some cases, respite care can make family, friends, and other informal caregivers better able to sustain the efforts and stresses of caregiving, thereby avoiding or reducing the expenses of home health nurses and other formal caregivers.

- <u>Expanded home health care, shift nursing, and personal care</u>: Medicaid provides these basic services with prior authorization. The expectation here was that HSCSN would provide them more flexibly, to remove barriers to care that might have run afoul of Medicaid regulations and practices but that made good sense for coordinating and integrating care.

- <u>Expanded medical supplies, equipment, and other medical appliances</u>: As with nursing care, such supplies and equipment were generally available under Medicaid with prior authorization. HSCSN was thought to be more flexible and innovative in what it could provide. Not least, HSCSN was expected to offer quicker approvals than Medicaid (days rather than months), which would permit improved care.

- <u>Pedialyte and other nutritional supplements when medically necessary</u>: Medicaid covers nutritional services, but within limits. HSCSN basically proposed to do so whenever these services would improve the patient's condition.

- Expanded dental services, including medically necessary orthodonture services: Medicaid limits its dental coverage in a variety of ways (e.g., elective surgery requiring general anesthesia and cosmetic surgical procedures are not covered). HSCSN proposed to consider surgical, orthodonture, and other services when they would have important consequences for the condition of the beneficiary.

- Expanded physical, occupational, and speech therapy consistent with habilitative and rehabilitative needs: These services were covered under Medicaid whenever progress toward established rehabilitation goals was likely. HSCSN proposed to cover these services even when rehabilitation as such was not the purpose (e.g., for maintenance purposes).

There were thus explicit commitments by HSCSN to care management, plus commitments to a set of services to be authorized on a case-by-case basis. On the latter, the effective extent of coverage depends on how frequently services are authorized or not, under what conditions. Accordingly, one continuing issue for qualitative and quantitative components of our evaluation will be to establish the processes of approval and frequency of utilization of these services.

3.2.2 Parent Reactions to Demonstration Benefits: Focus Group Results

Some of our most interesting information to date on the Demonstration benefit package comes from parents of children with special needs. In June 1997 we conducted six, 90 minute focus groups with parents of eligible children.[23] The discussion in these groups focused on parent perceptions of the marketing and enrollment efforts and processes employed by the Demonstration.[24] One group of parents were randomly chosen and recruited from HSCSN's list of families who had been contacted by HSCSN, but had decided not to enroll the eligible child. The other five groups were recruited from HSCSN's enrollment list. These groups of enrollees were chosen more systematically. We used the primary diagnostic information that was available on children enrolled in HSCSN. All children were initially classified into one of five diagnostic groups to reflect different types of service needs. Once classified into one of the five groups, 12 children were randomly chosen. The first group of children were those with acute and terminal illnesses such as various forms of cancer and HIV/AIDs. Without claims information for verification, it was believed that this group would represent heavy users of inpatient services. The second group were those with a mental illness diagnosis such as emotional disturbance or schizophrenia. Children with cerebral palsy comprised the third group while the fourth group was made up of those with respiratory conditions such as asthma and other pulmonary conditions. The last group represented children with diagnoses of mental retardation and developmental delays. Across the six groups, 38 parents attended.

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[23] For the sake of brevity, the word "parent" is used to describe the individual who serves as the primary caregiver of the child and hence, refers to both parents and legal guardians.

[24] Subsequent focus group studies will explore parents' reactions to the benefit package in greater detail and their appraisal of service delivery under the Demonstration, including the case management process.

The main finding of the first focus group study that we conducted with parents of enrollees is that the decision whether or not to enroll was most closely related to perceptions about the accessibility and quality of services that HSCSN promised to provide. Gaining timely access to services was a major concern of most parents. Therefore, HSCSN's transportation benefit was the principal deciding factor for many parents, who welcomed being relieved of the constant worry over trying to find transportation to and from appointments. One parent observed that, with HSCSN, "Parents don't have to worry about how to get your child to services if you don't have transportation. [HSCSN] will provide transportation immediately."

Another reason parents cited for enrolling their children was HSCSN's promise to assist parents to access services promptly by coordinating care, making appointments, and providing other aspects of care management. Some parents had specific needs that they anticipated HSCSN could address. For example, one mother was excited by the prospect that the HSCSN care managers could assist her child to obtain the appropriate special education services. Some parents had been frustrated by the complicated paperwork, long waiting times, and difficulties in obtaining specialized equipment or services (e.g., braces or psychiatric assessments) that characterized their experiences in Medicaid prior to joining HSCSN. These parents were encouraged to enroll because the HSCSN membership card offered them relatively easy access to these services.

Most of the parents cited the caring attitude of the providers as one of the criteria by which they judged the quality of care. Accordingly, many participants were prompted to enroll their children because of the caring attitude of the outreach workers and care managers. These representatives appear to be crucial in selling HSCSN, because they are often parents' first points of contact with the plan and, therefore, exert considerable influence on the enrollment decision. Parents spoke of the compassionate treatment they received from outreach workers, who appeared to understand genuinely their stress and concern over their children's health. Others reported that HSCSN gave them a general feeling that they would receive help whenever they needed it. Or as one participant stated, "If I need services, I'm pretty sure they'll help me."

Finally, for a few parents, it was especially important: (1) to learn that their child's primary care provider was a member of HSCSN's network, or (2) to have the child's primary care provider recommend that they join HSCSN.

Overall, these appraisals by parents who joined HSCSN suggest that the premises of the Demonstration were sound as first implemented. In particular, these parents give credence to the view that the more flexible benefits of the Demonstration--benefits depending less on arbitrary limits and more on purposeful management by a risk-bearing private provider--could directly address some of their most difficult problems in obtaining care in the fee-for-service system.

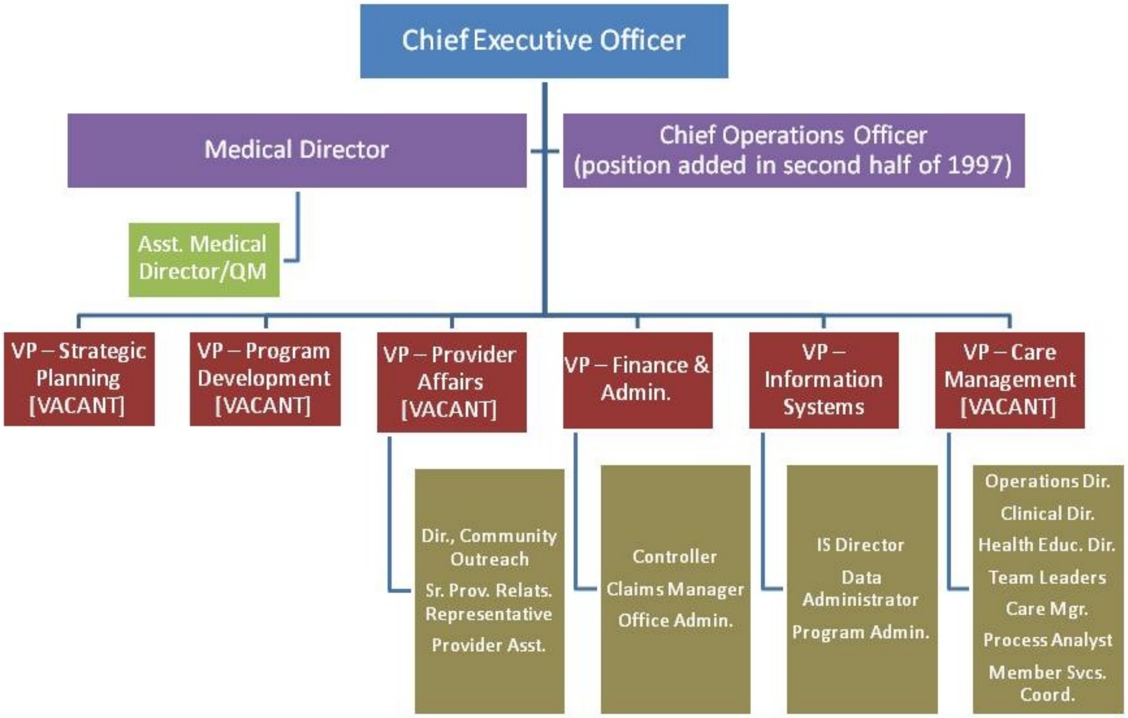
3.3 HSCSN's Structure, Staff, and Objectives

We have spent much of our early data collection effort on understanding HSCSN and its means of support for the ambitious goals of the Demonstration. We begin with a review of HSCSN's objectives, then turn to more descriptive information on the structure, staffing, systems, and other features of the organization.

3.3.1 Structure

The organizational structure at HSCSN is summarized in Figure 3-1. HSCSN has had one Chief Executive Officer since it was incorporated. Until recently, all of the main units of the organization reported directly to the Chief Executive Officer. There were six vice-presidents over functional and support units of the organization: strategic planning, program development, provider affairs, finance and administration, information systems, and care management. In addition, the position of Medical Director reported to the CEO and oversaw clinical issues and quality control and monitoring. Certain units had important dual reporting responsibilities: perhaps most important, care management teams under the Vice-President for Care Management also reported to the Medical Director for oversight of clinical issues in the course of care management business.

FIGURE 3-1. Organization Chart for HSCSN as of November 1997



3.3.2 Staff and Senior Staff Turnover

Until recently, senior management at HSCSN was relatively stable. However, as shown on Figure 3-2, four senior managers departed in 1997, and these positions were vacant as of the last quarter of 1997: strategic planning, program development, provider affairs, and care management. In the case of care management, the position had previously turned over less than a year before. The other positions had been relatively stable since the beginning of HSCSN's existence. Meanwhile, the position of Chief Operating Officer was created at about this time and filled in approximately August 1997.

This many changes in senior management at roughly the same time can come for many reasons. One hypothesis is that the organization has reached a natural break point in its development: the startup period is over, and senior managers can depart at this point with minimal disruption. A second hypothesis is that the turnover reflects a change in direction within the organization that has caused divisions of opinion among senior managers (e.g., over the future direction of the organization). A third possibility is that the turnover is merely a coincidence.

We cannot document coincidences, but we can shed some light on the two more substantive possibilities. As to the first possibility, it is true that 1997 constituted a pause in the organization's development, in the sense that the first operational year had been completed, the census had grown and stabilized, and future work dealt not with startup but something closer to steady-state management. As to the second possibility, the changes do more or less coincide with the appointment of a new Chief Operating Officer, and the latter may indicate the prospect of changes in direction or emphasis as might provoke differences of opinion among senior managers.

But we do not have any firm evidence on the matter. The important point to note here is that such turnover may be a sign of impending changes in direction at HSCSN and bears watching in the future.

3.3.3 HSCSN's Objectives

In appraising these staff and other changes, we should step back and consider just what HSCSN's objectives might be in this Demonstration. Consider the origins of the project. One catalyst for the project was parents' complaints (at the NACHRI conference) about the difficulties of dealing with a fragmented, fee-for-service Medicaid benefit, and the absence of any existing managed care alternatives to address their problem. A second catalyst was HSC's need to adapt to a health services environment increasingly dominated by managed care solutions, even as the hospital and its programs had little experience as part of managed care networks or as a care manager.

FIGURE 3-2. HSCSN: Tenure of Senior Staff

HSCSN Staff	Q1 ‘94			Q2 ‘94			Q3 ‘94			Q4 ‘94			Q1 ‘95			Q2 ‘95			Q3 ‘95			Q4 ‘95			Q1 ‘96			Q2 ‘96			Q3 ‘96			Q4 ‘96			Q1 ‘97			Q2 ‘97			Q3 ‘97			Q4 ‘97		
CHIEF EXECUTIVE OFFICER																																																
CEO 1		▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨
MEDICAL DIRECTOR																																																
M. D. 1	?	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨
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Asst. M. D. 1	?	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨
CHIEF OPERATING OFFICER																																																
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VP-STRATEGIC PLANNING																																																
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VP-CARE MANAGEMENT																																																
VP-CM 1		▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨										
VP-CM 2																																						▨	▨	▨	▨	▨	▨	▨	▨	Vacant		

SOURCE: Health Services for Children with Special Needs, Inc., 1997.
NOTE: A question mark indicates that a precise date is unknown. Vacancies are as of the middle of the last quarter of 1997.

Given these origins for the Demonstration, HSCSN is likely to have multiple objectives in the experiment. HSCSN may be animated by a commitment to deliver managed care benefits to care management in the District. At the same time, however, HSCSN may view this Demonstration (or may have come to view this Demonstration) as a way to do product development in an urgent area for an HSC entity that was somewhat behind the times: i.e., to develop and field test a managed care infrastructure to fit the new competitive environment, rather than an improved method for cost-effective care as such. One reason to take the hospital's strategic self-interest seriously is that many of HSCSN's activities are more easily explained if we broaden our specification of HSCSN's objectives:

- HSCSN made substantial investments in project infrastructure, especially for systems. These investments are difficult to explain if the Demonstration was an end in itself. HSCSN seemed to be developing and testing technologies of care management, rather than simply following the least cost path to serving the Demonstration population. If HSCSN's objectives were limited to making this Demonstration work, it might well have invested more in personnel and less in untried systems, especially since the key care management information system would not be available until the last year of the Demonstration. (It is worth noting, however, that HSCSN's interest in those systems extends only to internal use and the recovery of its development investment--the software developer retains profits on future sales beyond that.)

- HSCSN has set up a for-profit subsidiary funded by HSCSN to market the managed care capabilities HSCSN has developed. We do not know much about these marketing efforts or about the products that are being marketed. But the existence of such efforts suggests (unsurprisingly) that HSCSN has objectives that extend beyond this Demonstration and these District beneficiaries.

Figuring out HSCSN's "purposes" is not possible or important beyond a point, and the organization (and the people in it) doubtless have many different purposes at once. Meanwhile, there should be no innuendo here. A provider would be foolish to make this kind of investment of scarce people and resources, without some kind of larger strategic objectives in mind. Unless the Demonstration somehow suffers for these larger objectives, there is nothing wrong with them; and we have no evidence that the Demonstration has in any way been deprived. But the question of HSCSN's objectives will be important for understanding HSCSN's actions as the Demonstration, and our evaluation, proceed. As we elicit and sift information, we need to pay attention to the hypothesis that the Demonstration is as much a means as an end. HSCSN and its parent organizations may not be looking at this Demonstration as a stopping point, but rather as a platform to become something else. Obviously, such considerations are likely to affect some choices they make.

3.4 Systems

To set up HSCSN, five core administrative systems were required:

1. Internal network (email, etc.)
2. Payment systems
3. Credentialing systems
4. Quality management systems
5. Care management systems.

According to a senior HSCSN manager, the first four of these systems were relatively easy. The fifth system, critical to HSCSN's role as an integrator, was the difficult system to design and implement. As it turned out, HSCSN had to be a major systems integrator, which proved to be a very expensive role. However, while systems development is expensive at the start, "once you do it, you're much better off," an HSCSN senior manager believed. The issues here appear to be twofold:

- How does the task HSCSN is attempting to do fit the off-the-shelf systems already available in the market--and what does the answer to that question suggest about what HSCSN is trying to do? HSCSN could find no off-the-shelf system to support the care management process it envisioned. We are in no position to second-guess that judgment of commercial systems. But the absence of any adaptable system on the market might at least suggest that the kind of care management this Demonstration envisioned was indeed different than the models customarily supported by commercial software and systems developers. The managed care that this Demonstration sought to implement was for a population with special needs generally unserved by managed care options anywhere. It is plausible, without knowing more, to hypothesize that the needed systems would not already have been developed. What we need to do as evaluators is to make sure we can specify concretely how the task of these care managers differed from the extraordinary array of case managers already active in the health services system.

- What do HSCSN's system development activities suggest about HSCSN's objectives? Across a broad range, staff can substitute for systems. There are limits: such substitution would not necessarily yield the same kind of product possible with an automated system-e.g., the same kind of protocol enforcement and quick review possible in an online system. That HSCSN sought to develop a more sophisticated technical infrastructure (at considerable initial expense to itself, as discussed in Section 3.5 below) suggests a longer-term view of the Demonstration and a commitment to putting in place a new technology for service well beyond this Demonstration.

These conclusions will emerge more clearly from a detailed discussion of systems developments at HSCSN. We will review each of the major systems capabilities required, but focus on the care management systems. First, however, some background will be useful.

3.4.1 Background

In July 1995, HSCSN's new Vice-President of Systems joined the organization. At that time, there were still doubts as to whether the waiver would be awarded. This caused problems in developing systems to support HSCSN's prospective work. An internal Information Systems Steering Group had been set up as the vehicle for corporate oversight and decision-making on systems issues. The steering group was composed of nine people: a member of HSCSN's Board, the CEO, the VP Strategic Planning, the VP Care Management, an outside lawyer, an outside systems consultant, a technical consultant, and two outside health care consultants.

Initially, the new VP for Systems worked on two matters: (1) setting up the internal network and applications; and (2) from July to September 1995, evaluating products that were currently on the market for care management, verification of credentials, and claims. When the waiver was finally awarded in October, there was a rush to find the most reasonable software that could be implemented as quickly as possible, given the need now impending to support actual operations.

3.4.2 Internal Network

The internal network was purchased off-the-shelf. Selection and installation were not difficult.

3.4.3 Claims Package

The claims system was HSCSN's first priority and was the most important to implement quickly. Off-the-shelf products cost approximately $100,000 and would require 12-18 months to install. Instead, HSCSN chose a processing/data storage service, provided by Resource Information Management System (RIMS), a company based in Naples, Illinois. RIMS offered many advantages over off-the-shelf claims packages. HSCSN needed only to have a network connection to RIMS' data processing center and would not have to install any new hardware or to allow room to store claims files. Partially as a result (and especially important in view of HSCSN's few-month timing), RIMS had the shortest turn-around time. RIMS employed data center technicians 24-hours a day to help clients with problems. Not least, the RIMS rates were reasonable: HSCSN pays a member rate of $2,500 a month.

According to HSCSN systems staff, RIMS meets all of HSCSN's claims needs. The claims center stores information on capitation payments, HCFA's UR forms, and other critical claims-related information. In addition, RIMS provides HSCSN with capabilities to make claims and data queries on-line. Two HSCSN systems staff took a two-week training course to prepare for using the RIMS system. The system was up by February 1, 1996. HSCSN claims to have had minimal problems with the system. As of

September 1997, the system had been down only once, and that was because the telephone carrier was down.

3.4.4 Credentialing Package

HSCSN's Provider Department needed to be able to verify that the providers being recruited had the required credentials and licenses to join the network. To that end, an administrative assistant set up an Access database that served as a provider directory with the ability also to track the status of providers' credentials. This database was not sophisticated enough to meet the needs of the provider network recruiters, but it was a start. Later, HSCSN purchased a FoxPro-based package, SWEETQ, from a Texas company. This program augmented the Access database. It gave HSCSN on-line capabilities to access the National Practice Data Bank (NPDB) to verify information on the providers listed.

As HSCSN's provider network expanded, it outgrew these initial credentialing packages. HSCSN is now (fall 1997) making a transition to a more sophisticated package, CACTUS-1, which will replace the Access database and SWEETQ. The transition to CACTUS-1 reportedly has been difficult, largely due to complexities in moving files from the Access database into the CACTUS-1 system.

3.4.5 Quality Monitoring

At this point we know very little about HSCSN's quality monitoring system. As part of our subsequent evaluation work and following Demonstration activities, we will focus more closely on the provision of care, including care management activities, and how HSCSN and the District monitor these activities.

3.4.6 Care Management (CM)

The development of a care management system has been, by far, the most difficult of the systems developments for HSCSN. At the time the waiver was awarded, there were only a few commercial packages available for care management. HSCSN staff were looking for a package that would store planning information and information on contacts between the Care Manager and client. They also wanted a system that could outline schedules from past medical and contact history and track the course of approved care against protocols embedded in the system. Systems staff found that most commercially available software packages were targeted at medical offices and were generally designed for managing utilization and cost only. These packages were not designed for the kind of prospective care management the Demonstration envisioned, possibly (HSCSN staff hypothesized) because HMOs do not commonly manage care for children with special needs.

As an interim solution to support care management, systems staff initially chose to rely on an adaptation of Lotus Notes, because of its user-friendly interface and flexibility. But Lotus Notes had important limitations and could not be the basis for a longer-term care management system. Its role was mainly to capture data before the permanent system was installed. It was crucial to have some kind of working system prior to December 1, 1995, in order to capture information from the District's initial recruitment mailing. The permanent long-term goal was to have a CM package that would store contact information as well as generate prospective treatment plans for the clients.

HSCSN had a hard time finding a developer to meet its needs. Internal efforts to develop such a system before the new VP for Systems arrived in mid-1995 had been largely unsuccessful. During an industry conference in April 1996, HSCSN was introduced to Managed Care Systems (MCS). MCS had experience building packages for managed care organizations in Visual Basic. HSCSN decided shortly thereafter to work with MCS to develop a care management system for HSCSN. This effort would combine MCS' computer expertise and HSCSN's "domain expertise" to develop a customized package. The financial arrangement between MCS and HSCSN provided that HSCSN would have free use of the package that MCS and HSCSN developed, and that HSCSN would be able to recoup its development investment in subsequent sales. However, MCS retained ownership of the package and right to all profits beyond those specified for HSCSN.

According to HSCSN senior managers, this was not an easy decision, but the alternative was worse. The alternative was either to purchase a package off the shelf and request that the manufacturer make some changes, or to purchase several packages and try to patch them together, possibly with manufacturers' help. Given its small size, HSCSN did not think it could realistically get the attention of a substantial software or systems developer. Modifications of existing systems thus were not thought feasible for meeting HSCSN's needs in the long run.

With the help of MCS, HSCSN began in 1996 to develop software with on-line capabilities. The new system will provide a data repository and a communications log for Care Managers. The system will also provide checks and balances between the Care Managers and the business rules of HSCSN and will allow HSCSN to monitor trends in utilization and management. It is also expected by HSCSN managers to be capable in the future to be used for quality improvement, utilization review, and cost-containment.

In the new system, each request made by a member/provider must correlate with a situation, issue, or goal cited in the current Plan of Treatment (PoT). The new system makes it essential that the PoT accurately and completely represents a member's situation, a demanding standard. Because of the nature of the initial assessments, HSCSN recognizes that there will be a lot of adjustment after the first PoT. According to HSCSN, this new emphasis on the PoT is planned to bring about more fact-based data and ease in planning the care of a member.

The software will permit detailed structuring of selected treatment decisions. For example, if a Care Manager approves treatment outside the bounds of HSCSN policy, the system will flag the disparity and either: (1) automatically route the matter on-line to a senior care manager (e.g., Team Leader or Medical Director), or (2) in some cases, disallow the request and block the forwarding of the request to a senior manager (e.g., if the situation falls outside the boundaries of HSCSN policy to allow extra stays, or if the Care Manager does not completely fill in the request).

Senior HSCSN managers and systems staff have commented that the development of such a sophisticated package may decrease the necessity for Care Managers to have clinical expertise. That is, they claim that the system will automate the care management process to some degree and eliminate the need to have "an RN at every station." The system is said to provide the Care Managers with the guidance that they will need in order to make decisions; decisions will in turn only go to Team Leaders or the Medical Director when HSCSN policies so require. The system will in that sense serve to keep everyone within the process. The ultimate issue here is who is responsible for monitoring human judgment about differences between care decisions and care protocols. When this system is in place, "exceptional" decisions will be systematically monitored. It will then be possible to tell how much of the care being provided was planned (in the PoT's) and how much was added. HSCSN hopes to be able to use this system to figure out how to improve the planning of care. The value of the system in that role remains to be seen.

HSCSN has had one care manager solely devoted to helping test this new package, as the live operation date approaches. Before the package is fully implemented, HSCSN must "dump" the historical data from Lotus notes into the new package. As of September 1997, HSCSN planned to "go live" by November 1997. This date had been pushed back gradually from the original start date of April 1997. Obviously, we will need to follow the implementation of this system and how it affects HSCSN's staffing and management of care, as it is based on a series of assumptions that may or may not be proved correct by actual practices.

Senior HSCSN managers believe that--when states are forced to incorporate comprehensive care planning within their mandated HMOs--there will be a larger market for this kind of product. At the present time, all HSCSN can do is recommend the package to others. HSCSN is also aware of new packages out on the market similar in form to what HSCSN and MCS have developed. The new packages are said to be diagnosis-specific (e.g., a Microsoft care management tool for breast cancer). Eventually, an HMO would have to merge these fragmented packages, and the need to merge these packages may make HSCSN's domain expertise more marketable.

3.5 Financial Performance

The financial performance of HSCSN is of obvious significance for assessing the practicality of the Demonstration model, at least in the specific form (and under the specific terms) that the model was implemented. In this section, we review three financial issues raised by the Demonstration: startup costs, capitation rate and risk sharing, and operating results to date.

3.5.1 Startup Expenses

Original projections for startup costs proved to be substantial underestimates: actual startup costs (intangible assets) were $4,986,897,[25] a figure many times the original estimates.[26] Some of the overrun is attributable to the protracted development and negotiation period after the waiver application was submitted. Consider: HSCSN's originally predicted startup date was approximately August 1994, just a few months after the waiver application was to be submitted. This early startup date was the basis for the original estimate of startup costs. But the actual startup date (the date when the first group of enrollment packages was sent) was December 15, 1995--i.e., actual startup was almost 16 months later than original projections assumed. Simply carrying administrative overhead for this additional period was expensive. For example, expenses for rent alone for the extended period were perhaps $0.3 million.[27]

But some of HSCSN's cost overrun on startup was due to startup activities that were not taken into account in the original estimate. For example, original estimates assumed that all systems would be acquired off-the-shelf, with minimal adaptation expense (e.g., perhaps $0.1 million). As it turned out, development expenses for the care management system alone were approximately $2.0 million. We are not in a position to second-guess these choices regarding development and overhead costs, since we really do not know (nor will we know) all that was involved, such as what the alternatives were, what they cost, and what the consequences were expected to be. We raise these points to emphasize that--in appraising the results of the Demonstration to date--we should be aware that the model as implemented appears to be a substantial commercial venture, not a bare-bones or temporary venture.

3.5.2 Capitation Rate and Risk Corridors

As noted in Chapter 2, the capitation rate for this project was based on estimates made from historical claims records. Initially, HSCSN proposed capitation rates in the range of $1,200 to $1,300 per member per month (PMPM). But after the District carved out certain high-cost items (such as transplants and District public school services), the rate came down below $1,000 (ultimately to $997.71 for the "first year"; i.e., for the period of December 1, 1995, through September 30, 1996).[28] This rate was then to be

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[25] Actual startup cost data from "HSCSN Depreciation Worksheet Summary," provided by HSCSN to Abt Associates, undated. The intangible assets indicated exclude $28,609 in leasehold improvements. Also excluded from the startup costs figure is nearly $800,000 in depreciable fixed assets, including $89,327 in furniture and equipment, $107,329 for the phone system, $363,240 for computer software, and $218,232 for computer hardware.

[26] Projected startup costs are noted in "Original Task Force Report, January 1994: Five-Year Annual Projection," prepared by Lewin-VHI, dated January 18, 1994, provided by HSCSN to Abt Associates.

[27] This figure is a crude estimate of rent paid during the extended startup period--i.e., from August 1994 (HSCSN's expected startup) to December 1995 (the actual startup). The estimate is based on a total startup rent of $358,133, as described in Coopers & Lybrand, "Report of Independent Accountants," for the year ended December 31, 1996, Note 1 to the Financial Statements.

[28] The period ends in September to coincide with the end of the fiscal year.

trended for inflation and the "prior year experience" (after much discussion with HCFA, a 4.6% inflation rate was agreed).[29] The rate for the following twelve months through September 1997 was $1,043.61 PMPM, which represented a simple inflation adjustment of the initial rate. The new rate in October 1997 was $1,067.60, representing an increase of one-half of the full inflation adjustment, based on the relatively favorable financial experience to date (see below).

These basic capitation payments were to be reconciled annually according to the provisions of a risk-sharing agreement between HSCSN and the District, set forth in the November 30, 1995, contract between HSCSN and the District. This agreement sets up an 85% medical claims ratio as the target for the Demonstration, where medical claims ratio is defined as the ratio of actual claims expense for covered services, divided by the total capitation payments for each year of the Demonstration. The District shares varying levels of risk in corridors around the 85% medical claims ratio target, as shown on Table 3-1. The calculations are made on a fiscal year basis, not calendar year.

Note that these risk corridors are not arranged around surpluses and losses as such, but rather around varying ratios of covered medical expenses to total revenues. The basic assumption is that, with administrative costs at 85% of capitated revenues, the provider will more or less break even. If medical expenses substantially exceed expectations, the claims ratio will be unexpectedly high, and the District's share of the excess expenses will increase as the claims ratio increases. If the claims ratio is unexpectedly low, the District will receive an increasing share of the shortfall (i.e., a refund of an increasing portion of the capitation payments) as the claims ratio decreases. While these variations around the 85% target do not translate directly into losses and surpluses to HSCSN, results to date (Section 3.5.3 below) show a fairly close relationship: claims ratios have been between 82% and 85%, and accounted losses have been slight.[30]

Given this structure of risk corridors, the provider is put in a position to avoid big losses, if costs are unexpectedly high. But big gains are also attenuated by the sharing arrangement for shortfalls if the claims ratio is below 85%.

For both the Federal Government and the District, there are upper limits on what can be paid under the Demonstration:

- Federal financial participation is required to be "budget neutral," so federal payments can be no greater than the estimated payments that would be made in the absence of the waiver. This standard applies: (1) over the full three-year

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[29] Details of the financial terms ultimately established are from Agreement between the District of Columbia (CHCF), and Health Services for Children with Special Needs, Inc., dated November 30, 1995, Article 7. The inflation terms are detailed in HCFA, "Health Care Financing Administration Special Terms and Conditions," project no. 11-W-00021/3, dated October 13, 1995.

[30] These accounted losses are computed according to generally accepted accounting principles, rather than the cash basis used to calculate risk sharing.

Demonstration, not year by year,[31] and (2) to the capitation amounts, not the total dollar amounts, so the District is not at risk for the number of enrollees.

- The capitation fees and other payments by the District cannot exceed the cost of providing those same services on a fee-for-service basis, to an actuarially equivalent nonenrolled population group.[32]

TABLE 3-1. Managed Care Demonstration for Special Needs Children: Risk Sharing Corridors between the District and HSCSN

Medical Claims Ratio as a Percent of Capitation Revenues							Percent of Risk Assumed	
Lower Corridor Boundaries			Target	Upper Corridor Boundaries			District	HSCSN
						> 95%	85%	15%
					→ 95%		50%	50%
				→ 90%			15%	85%
			85%				0%	0%
		80% ←					15%	85%
	75% ←						50%	50%
< 75%							85%	15%

SOURCE: Agreement between the District of Columbia (CHCF), and Health Services for Children with Special Needs, Inc., dated November 30, 1995, Article 7.

Given these limitations, the effective payments to HSCSN could vary widely, depending on the financial outcomes of the Demonstration. In particular, the payments calculated under the risk-sharing formula as described earlier could be superseded by these special caps.

It is a tricky matter to predict the incentive effects of a financial arrangement like this one. The key question for the evaluation is whether the incentives are: (1) sufficient to animate the provider toward the farsighted, active performance that the Demonstration model assumes, and (2) whether those provider activities improve care and reduce costs. More concretely, for example, are the incentives under the established arrangement sufficient for HSCSN to encourage or keep the pressure on the MDTs to manage care in new ways? Does this new MDT management improve patient care? It is no exaggeration to say that, if the MDTs do not concretely provide new forms of collaboration and coordination among separate providers and services, then the "management of care" in this Demonstration will be limited to rhetoric. However, as has been suggested in a variety of other contexts (e.g., in the care of frail elders),[33] multi-disciplinary collaboration can provide critical forms of collaboration that promise to be cost-effective in that they can improve care and reduce costs. It remains to be seen whether the incentives are structured in just the right way here.

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[31] HCFA, "Health Care Financing Administration Special Terms and Conditions," project no. 11-W-00021/3, dated October 13, 1995, Attachment D. However, note that the District is required to prepare corrective action plans if the expenses exceed budget neutrality estimates by specified percentages each year.

[32] Agreement between the District of Columbia (CHCF), and Health Services for Children with Special Needs, Inc., dated November 30, 1995, Article 7.F and 42 CFR §447.361.

[33] E.g., see Abt Associates, Cross-Site Analysis of the PACE (Program of All-Inclusive Care for the Elderly) Demonstration: Calendar Year 1993, report submitted to the Health Care Financing Administration (March 17, 1995).

The important points to note are that:

- Much as the Demonstration model assumes, there are incentives in place to encourage the provider to economize in beneficial ways.

- But except in broad terms, the actual effects of this incentive structure are not simple or necessarily correct.

These observations could probably be made about the incentive structures in any capitated arrangement (or, for that matter, in almost any demonstration that, like this one, fundamentally modified the terms of program payments). The incentive structures for actual managed care demonstrations are never unambiguous in their effects, whatever the abstract design. Such issues will remain important questions for us, as our evaluation proceeds.

3.5.3 Financial Performance of HSCSN to Date

Notwithstanding the scope of possibilities, the actual results to date in the Demonstration have been fairly close to initial projections. The way the agreement between the District and HSCSN is written, the risk sharing calculations are done strictly on a cash basis, with some allocation of care management costs. In fiscal year 1996, the medical loss ratio was approximately 82%, as against a target ratio of 85%. Under the terms of the agreement, this shortfall meant that HSCSN should pay approximately $0.2 million back to the government, out of the gross capitation revenues. HSCSN has been trying to settle with the District over 1996 risk sharing since June 1997 and has accrued funds to pay the District. As of our last round of interviews, however, the settlement was not complete; and the District has indicated that it wants to audit HSCSN financials, but there has been no audit as yet.

For fiscal year 1997, which ended in September 1997, an HSCSN financial manager estimated the loss ratio to be in the same vicinity: i.e., 82% - 84%.

These results provide a first-order test of the assumptions of the Demonstration, and the message here is that the results approximate the assumptions. We have not done an independent financial analysis (we will not be doing one), but we can report what senior managers of HSCSN have described as the reasons for these consistent results:

- Lewin did a good job of estimating the costs of serving the population.

- The District-HSCSN agreement calls for a 61-day cutoff on claims after the end of the fiscal year, for purposes of the risk-sharing calculation. As it happens, providers have been slow to submit claims (some providers take as long as a year to submit claims), which has the effect of reducing the apparent medical claims ratio. This pace was a surprise to HSCSN, although it is not clear that it surprised CHCF.

- Active management of care for this population made it possible to save money. In particular:
    - Decreased hospital admissions and lengths of stay (lengths of stay were cut by 14% - 20% against baseline data). HSCSN tried to substitute homecare for hospital care (with the result that less expensive homecare costs for the population increased "dramatically").
    - "Huge" decrease in emergency room use, by educating beneficiaries and their families, by making Care Managers available by phone 24-hours a day, by making phones available to those without them, and by educating providers.
    - Use of the District Fire Department as the ambulance service.
    - Use of preventive care, such as consistent EPSDT screens, dental care flags every six months, and others.
    - Closer supervision of specialists, especially mental health specialists.
    - Early in the Demonstration, hospitals were paid per discharge, and that created an incentive for hospitals to admit beneficiaries from their emergency rooms. Now, HSCSN pays per diems instead, thus reducing the incentive for unnecessary admissions.

- Ironically (in view of the opposition of day treatment centers to the Demonstration), total dollars going to DTCs is little changed from before the Demonstration.

- Some aspects of the Demonstration tended to increase costs. For example, HSCSN pays providers within 20 days of a clean claim. In the fee-for-service system, the District pays providers in 60 - 75 days on average. Paying more quickly reduces HSCSN's cash flow.

Throughout the rest of the evaluation period we will be confirming these explanations through analyses of Medicaid and HSCSN claims data. At that time we will be able to better define the extent of changes in hospital admissions, homecare, emergency room use, and other types of service use.

Meanwhile, there have been unexpected financial issues between the District and HSCSN. Most often, these problems have arisen out of the limitations of District systems. Data problems in the District have complicated initial contacts (see Chapter 5 below) and also brought about difficulties in allocating responsibilities for the costs of some care. For example, in April 1997, HSCSN noticed that the child baseline utilization and medical loss ratios were running lower than expected--thus leading to the natural inference that some utilization was leaking out of the HSCSN system, into the conventional Medicaid system. HSCSN hired 8 temporary claims examiners to audit the members' claims. Based on First Health's data, the examiners discovered that some Demonstration enrollees were still using their Medicaid cards, and District eligibility systems and First Health payment systems were not catching the mistake. (Apparently, providers check a system called EVS, in order to verify a patient's eligibility. The District maintains this system and had failed to change the status of HSCSN's members.) The claims were largely from 1996, with a small amount in 1997. Because of this systems problem, DC Medicaid had been paying for roughly $2 million dollars worth of services that should have been paid for by HSCSN. But these beneficiaries were outside the HSCSN system when they obtained the services, because District systems had not worked properly. As a result, HSCSN could not manage this care. The District and HSCSN negotiated a 50% reduction in the amount HSCSN owed, to account for the loss of potential savings from HSCSN's management of these cases. The District corrected this systems problem to prevent a recurrence, so that these claims are now submitted to HSCSN.

There are thus a variety of different factors behind HSCSN's financial performance to date. Meanwhile, apart from indirect data (e.g., suggestions of satisfaction from parents in our initial set of focus groups), we have little information as yet to describe whether financial performance close to targeted levels is due to accurate prediction of cost-effective operations or to more arbitrary management of care and other operations to meet the targets--and if the latter, whether the underlying rates and types of utilization needed to meet the targets are satisfactory. Such information will ultimately be needed. For now, however, the financial results provide a first-order reassurance of the practicality of the model.

While HSCSN has more or less broken even in terms of the cash basis of the risk-sharing adjustments, audited financial statements show a large loss, principally due to the amortization of startup costs. As shown on Table 3-2, HSCSN lost $1.7 million in calendar year 1996 and (if finances through July 1997 are annualized) faces a loss of approximately $0.4 million in calendar year 1997.[34] According to a senior HSCSN manager, HSCSN would be making a small profit on a current basis under standard accounting methods, but for the amortized startup charges.

3.6 Relationship to Other Service Systems

The pre-Demonstration matrix of providers and programs is intricate. Any carved-out initiative like this Demonstration is bound to be less than comprehensive--i.e., to omit at least some programs and providers important to the target population. But some carve-outs are a more natural fit with the larger system than others. Especially in a demonstration where integration of services is the fundamental promise of the initiative, it is important to ask how the Demonstration relates to other service systems. Has there been coordination at the important boundaries of the Demonstration, where there is no formal authority or responsibility? Three such systems are most important: the public schools, foster care, and mental and other health systems.

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[34] Note that these figures are for calendar years, not the fiscal years that are the basis of the risk-sharing adjustments described earlier; and these results are conventional statements of financial performance--e.g., including depreciation, amortization, and interest--not the cash-flow based calculations of the risk-sharing adjustments.

3.6.1 The District Public Schools

The District public schools have extensive responsibilities for children with special needs. While these responsibilities are based in the education mission of the schools, the public schools perform important health functions, to the point that in recent years (when schools and others began to look to Medicaid to fund these activities), the school system actually became a substantial Medicaid provider. It is easy to imagine some of these overlaps between educational and health activities--e.g., for children with special needs who require the support or observation of a nurse while they are instructed.

TABLE 3-2. HSCSN Financial Results to Date

Item of Revenue or Expense	**Calendar 1996: Audited Results**	**1997: Unaudited Results for January - July**	
		7-Month Results	**Simple Annualization**
REVENUE			
Per capita revenue, net of settlements	$7,907,947	$11,632,077	$19,940,703
Other revenue	57,538	241,781	414,482
Total	$7,965,485	$11,873,858	$20,355,184
OPERATING EXPENSES			
Program-Related Expenses			
Hospital costs	$2,374,066	$4,381,555	$7,511,237
Physician fees	217,772	536,174	919,155
Care management costs	1,632,156	1,492,273	2,558,182
Reinsurance	291,665	143,823	246,554
IBNR	---	797,776	1,367,616
Other medical costs	1,854,034	2,289,171	3,924,293
Subtotal	$6,369,693	$9,640,772	$16,527,037
Administrative Expenses	3,329,287	2,449,345	4,198,877
Total	$9,698,980	$12,090,117	$20,725,914
EXCESS REVENUE or EXPENSE			
Total Revenues - Total Operating Expenses	($1,733,495)	($216,259)	($370,730)

SOURCES:
1996: Coopers & Lybrand, "Report of Independent Accountants," for the year ended December 31, 1996 ("Statement of Operations and Changes in Net Assets," p.3; and "Functional Expense Classifications," p.9)
1997: HSCSN, "Discussion of Operating Results for Month Ended July 31, 1997," monthly report submitted to CHCF by HSCSN.

In the beginning, CHCF sought to coordinate the Demonstration initiative with the school system. Most concretely, CHCF hoped to include public health/school-based costs in the Demonstration funding. Ultimately, these school-based costs were not part of HSCSN's formal responsibilities. As a result, much of the hoped-for coordination would have to occur by mutual agreement. CHCF sought in 1994 - 1995 to obtain a memorandum of agreement from the District public schools. According to CHCF and HSCSN, the public schools have resisted all overtures from CHCF or HSCSN to collaborate in any way. We have attempted, so far unsuccessfully, to talk to school officials familiar with these issues. That discussion will be essential for us to develop a more detailed picture of these issues.

3.6.2 Residential Treatment Centers

One particularly troubling area at the boundary of many different public programs is residential treatment centers (RTCs). These centers provide supervised residential care for patients in temporary need of 24-hour supervision in an institutional setting. In the District, placements in RTCs can be generated from a number of different agencies: notably the school system, the courts, the Commission on Mental Health Services, and the Commission on Social Services (including child protective services and foster care). There are no RTCs in the District. All of the providers are out-of-area, some as far away as Texas. The placements are extremely expensive--each child in an RTC costs $125,000 per year per child on average--both because the daily rates are high and because lengths of stay are "tremendous," in HSCSN's words. These are extreme outliers among the District's health and social service expenditures, even as (from HSCSN's point of view) there appears to be little oversight of the RTCs to ensure that children are getting adequate care. There are an average of 260 children from the District in these facilities at any point in time.[35] Of these, 60 - 80 are SSI enrollees, 100 are foster care placements, and the remainder are placed by other programs. Note that, when a Medicaid-eligible SSI child is placed in a Medicaid-eligible facility--but placed for non-Medicaid reasons-- HSCSN does not pay for this care. HSCSN insists that it should not pay for care it cannot manage, and such management has been impractical when the placements are supervised by other agencies. It is a reasonable assumption that these RTCs are getting some of the most difficult and expensive cases among children with special needs. If so, placing these children outside HSCSN's responsibility biases selection for Demonstration enrollees, as against the assumptions made when the capitation rates were set.

The key issue is whether those rates should be revised, or whether HSCSN would take responsibility for these children if it could manage their care and supervise the providers. This solution would require taking these children out of the multiple service systems, rolling the dollars together, and then managing these placements when they are necessary. In interviews, we have heard HSCSN managers express a preference for taking over these cases; and senior CHCF managers have suggested the possibility of amending their agreement with HSCSN to include these RTC children. But according to CHCF, none of the other agencies involved is willing to entertain that kind of arrangement at the moment.

However, some progress is being made. There is in prospect a memorandum of understanding among CHCF, HSCSN, and the Commission on Mental Health (the ultimate guardian of many of these children). The most important uncertainty looming at the same time is that the Commission on Mental Health is about to enter court-ordered receivership, which could change the context for this understanding in critical ways.

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[35] The data in the text on RTC placements is from a special claims analysis done by HSCSN.

3.6.3 Foster Care

The foster care program is administered by the Commission on Social Services. There are roughly 2,700 foster care children in the District, a population of almost the same size as the children with special needs who are included in the Demonstration. Similar to children in RTCs, foster care children generally are outside the Demonstration because these children are typically subject to court ordered placements and services. However, there are points of contact between foster care and the Demonstration, as the previous section on RTCs suggests. The main significance of the foster care population is as a group to be added to the SSI group now in the Demonstration. If the Demonstration were extended, adding foster care children to the Demonstration would make it more feasible to have multiple contractors, which HCFA may require in any extension of the Demonstration.

The foster care population includes many children with special needs. But since foster care children were not included in the original base population and since they are under the jurisdiction of a separate agency, they cannot be folded into the Demonstration without some additional work being done: (1) to analyze the implications of including these children, and (2) to reach agreement with the foster care agency to have these children included. The foster care program is now operating under a court-appointed receiver, which might make it more feasible to establish the new arrangements that have to be made.

3.6.4 Public Health Clinics

Public health clinics were interested in collaboration initially. The network of clinics was being consolidated, so some clinics were closing. Meanwhile, Title V and other funding for the clinics was declining, and Medicaid had become a more important source of funding.

These clinics initially joined the HSCSN network. However, the clinics later withdrew (approximately April 1997). The primary issues between the Demonstration and the clinics concerned:

- **Credentialing:** The clinics did not want to comply with credentialing requirements for the Demonstration. While CHCF and HSCSN were willing to be flexible on how the requirements were met, they were concerned that a failure to achieve compliance guidelines would jeopardize forthcoming review by JCAHO.

- **Plans of Treatment:** The clinics resisted the PoTs and wanted some exclusions from PoT requirements.

When these issues could not be resolved, the clinics withdrew. These clinics were important primary care centers for some enrollees, so some members dropped out of the Demonstration after this decision.

3.6.5 Conclusion: Relationship of the Demonstration to Other Service Systems

HSCSN was chartered to integrate services for children with special needs, but that charter has been trimmed in important ways by problems at the boundaries of the Demonstration's authority. When we look at the schools, for example, the obvious conclusion based on evidence we now have is a pessimistic one. Integration of services for the children involved is notably difficult, as it can only be done ad hoc, child by child. And the splicing together of the Demonstration with one set of important providers for indigent children--the public health clinics--has ended in a rupture between the two systems, over issues that are serious to the agencies involved but doubtless rather puzzling to the parents affected.

But there are some encouraging signs in this experience. With the Demonstration, a contractor with a charter to integrate services was set loose on a very complicated system of services. That contractor's responsibilities did not mesh well with parts of the service system--e.g.,other agencies placing children in RTCs at great expense. In part out of the contractor's self-interest (i.e., its unwillingness to pay if it was not given authority to manage), some very troubling placements were brought to light. That revelation set in motion the political and policy work necessary to reach a possible memorandum of understanding with the Commission on Mental Health that may improve the care of these children. We will follow the progress of this coordination effort, as a lot must happen for these initial policy concerns to develop into substantial, concrete results. It may mark one of the unexpected ways that the Demonstration rationalizes care outside the immediate charter of HSCSN.

3.7 Relations of HSCSN to HCFA, CHCF, and the Community

HSCSN's relations with outside agencies and persons will have an important impact on what the Demonstration accomplishes. In this section, we will briefly review HSCSN's relations with three groups: HCFA, CHCF, and the community.

3.7.1 HCFA

As discussed in Chapter 2, HSCSN and CHCF had difficult relations with HCFA through the startup of the Demonstration. Since that time, relations with HCFA appear to have settled down, from the points of view of CHCF and HSCSN. The Demonstration is now up and running, there have been few complaints (as of late 1997), there is more vocal community and parent support, and providers (including the Day Treatment Centers that were so opposed at the outset) have adjusted to it. However, as the end of the Demonstration approaches (November 30, 1998), there are critical questions about the terms of continuation of the project. Continuation will require new understandings between CHCF and HCFA and will have important effects on HSCSN (most importantly, concerning how any continuation contract is awarded).[36]

3.7.2 CHCF: The Rewards and Risks of Collaboration

Relations between CHCF and HSCSN have been smooth, according to senior managers in both organizations. As one CHCF manager noted, CHCF has monitored this contract by interacting collaboratively with HSCSN and working together to solve problems. This collaborative relationship was contrasted to a more arms-length or formal relationship that CHCF might have adopted, whereby CHCF would invest its energy in tracking HSCSN performance against contract and other formal standards. A more collaborative arrangement was adopted, it appears, for three reasons:

- The District had little experience overseeing a managed care venture of this sort.

- Many of the administrative and systems problems the District faced made collaboration helpful and a more formal relationship difficult (and possibly inefficient). In effect, HSCSN could provide expertise and staff extensions to solve problems that arose, including problems of locating beneficiaries, establishing the cost and location of children in RTCs, helping to clean up the $2.0 million in claims of enrollees who continued to use their Medicaid card, and other problems. A more formal relationship would have set limits to this kind of contractor support. Given the fiscal crisis in the District and the relatively small staff overseeing this Demonstration (fewer than 10 people), CHCF may not have had much choice.

- The personalities of the lead contacts for CHCF and HSCSN.

These reasons for a collaborative relationship are unexceptional, if we make the assumption that the contractor is performing satisfactorily. We cannot claim to have reached an independent judgment on that issue. We do have preliminary evidence (e.g., from focus groups with parents) suggesting that the contractor's performance has been satisfactory to beneficiaries and their families. And while HSCSN and CHCF managers characterize their relationship in collaborative terms, it is not as if CHCF is taking everything at face value--for example, note CHCF's insistence on an audit of HSCSN, before CHCF will settle on the risk-sharing payments for 1996.

But it is worth pointing out the risk of the CHCF-HSCSN collaboration. If information were to be revealed showing actions in bad faith by the contractor (or agency staff), the collaboration might begin to look like a form of unwise co-optation. We will continue to review the character and effects of this relationship as the Demonstration proceeds.

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[36] The terms and conditions of the waiver (Section IV.C.1-2) accept non-competitive, sole source contracting for the first three operational years of the Demonstration. But for any continuation of the Demonstration, the District is required to implement a competitive procurement "open to all (managed care plans) that meet participation standards.”

There are likely to be some changes in the CHCF-HSCSN relationship in coming months. Key personnel (notably, the project manager) have left the project, and CHCF is reorganizing internally, with the creation of a new children's unit to coordinate and act as a focal point for children's programs in the commission. At the same time, the lead contact for the Demonstration at HSCSN is leaving that organization. We will follow and attempt to document the effects of these personnel changes.

3.7.3 The Community

Perhaps as a result of the efforts HSCSN had to expend to reassure the community at the outset of the Demonstration, the program has devoted considerable thought and resources to ensuring that the community is involved in the implementation of the Demonstration. The Demonstration has been able to forge linkages with advocacy groups, many of which are also service organizations, by inviting them to join the HSCSN provider network. Representatives from some of these advocacy groups sit on the HSCSN Community Advisory Board, along with care givers of HSCSN, members, providers, and Care Managers. This committee was established early in the implementation of the Demonstration, in part to forge ties that were once lacking with the community. The mission of this committee is to advise HSCSN on operational issues surrounding the delivery of care and coordination of services to members and their families.

HSCSN has also sought to involve the lay community and families of children with special health needs more fully than perhaps was the case during the planning of the Demonstration. The program has developed an outreach program which targets not only the prospective clients and their families but also the communities in which they live.

HSCSN hired outreach staff with expertise in the following areas: community relations and development, working with low income populations, and explaining managed care to low income populations. According to interviews (with outreach staff, clients, and advocacy groups) and findings from our parent focus groups, the background of the outreach staff has been crucial to the community's perceptions of HSCSN. Specifically, the staff's ability to explain managed care in an understandable way to members of a population that traditionally uses fee-for-service and to address their fears about the impact of managed care on the services their children receive has influenced many in the community to perceive HSCSN positively. HSCSN staff have employed two strategies to ensure community involvement. These are outreach and investment. A separate discussion of each strategy follows.

The first outreach efforts focused on several wards in the District where children eligible for the Demonstration were thought to be concentrated. HSCSN outreach staff gained entree into these communities by soliciting the help of the indigenous leadership in these wards. The indigenous leaders are the individuals who may not be prominent outside of their neighborhoods but who are respected, trusted, and influential within their communities. Relying on their prior experience with similar populations, HSCSN staff sought out leaders of local churches and tenant associations, educators, providers from local service delivery organizations, and advocates.

These leaders were assembled at several community briefings conducted by HSCSN. The purpose of these meetings was to inform the leaders about the mission, goals, and objectives of HSCSN, to answer questions about the potential benefits of the program, and most importantly to allay fears that the Demonstration could have a harmful effect on children's health or their access to services. Once the leaders were persuaded that the Demonstration could benefit their communities, they legitimized the outreach effort by passing along favorable appraisals of the Demonstration to audiences that respected them. Furthermore, in some cases they assisted in the identification of prospective clients. According to one HSCSN staff member, "the leaders opened parents' ears to our message; without their stamp of approval, we couldn't have made headway."

Although most of the leadership were contacted during the initial outreach efforts, the HSCSN staff have maintained their relationship with these individuals throughout the course of the Demonstration. Keeping the community leadership involved has been important because the outreach effort is ongoing. There is a constant need to gain entree and to reassure the community that the Demonstration is a benefit, not a threat, to children with special health needs. The outreach staff have also recognized the important role that HSCSN can play as a community partner, one which not only seeks clients but is also intent on giving something back to the neighborhoods from which clients are recruited. Therefore, the second strategy of community involvement that HSCSN has implemented is one of investment.

HSCSN invests in the community primarily through employing members of the community whenever possible and appropriate, and participating in and/or sponsoring health-related events. Many of the HSCSN outreach workers are members of the communities in which the Demonstration's clients reside. According to the respondents, this strategy has led the community to perceive HSCSN as an organization that is interested in community development. All of the outreach workers attend an intensive training session prior to commencing their duties. Some points covered in the training include aspects of public relations, cultural competency, and the terminology that is commonly used by providers to describe and discuss the design and delivery of managed care services. Since many of these individuals were unemployed and lacking marketable jobs skills prior to their employment at HSCSN, the training and the experience they gain as outreach workers has the potential to improve their future job prospects. Furthermore, the HSCSN outreach department has adopted an unusual but innovative practice of only offering these workers temporary, part-time positions. This approach may appear to undermine HSCSN's apparent goal of expanding the job market in typically under-served communities. However, according to the director of HSCSN outreach, by maintaining a continuous flow of community members in and out of the outreach department, HSCSN is able to train and provide job experience to more individuals. The outreach director observed that the workers are taught to view their positions as a step to more training and/or another career, possibly in health care. Workers receive certificates at the end of their training and employment with the program. According to reports, many have in fact used these certificates to obtain employment elsewhere.

Of course, not all members of the community seek employment. Therefore, HSCSN has attempted to involve these members in the Demonstration in other ways. Since the implementation of the Demonstration, HSCSN outreach staff have made it a practice to attend various health fairs and other health-related events that are held periodically in the District. Some of these events are targeted at children with special health needs and their families. Others target particular ethnic groups, while some are for the community at large. HSCSN has also sponsored and provided volunteers for some events independently (e.g., Special Olympics and puppet shows at local schools). In interviews, HSCSN staff report, and advocates and parents concur, that HSCSN maintains a family focus at these events and offers activities for adults and children of all ages, regardless of whether or not the event is sponsored by the Demonstration. HSCSN staff gear the information and activities they offer to entire families and seek to schedule their attendance to coincide with times (e.g. weekends or early evenings) when working parents might be able to attend. Respondents indicated that HSCSN's presence at these events has been crucial not only in raising public awareness of the program, but also, in the words of one advocate, "letting the community know that [HSCSN] is interested in whole families."

3.8 Conclusion: Implications of the Demonstration Design for Other States

The implementation of the Demonstration provides some important lessons for other states considering a similar initiative:

- The model itself has received encouraging responses from parents in our initial focus groups, suggesting that the basic premise of the Demonstration--that management and facilitation of care could improve how different components of treatment fit together--was a step in the right direction. At the same time, the fact that the financial performance of the contractor approximates original expectations provides a first-order reassurance that the assumptions of the model were practical.

- The lack of consultation with key community and provider groups appears to have exacerbated opposition to the Demonstration. We do not know how much opposition would have been quieted by a more conciliatory, more consultative approach. But even HSCSN and the District emphasize that more consultation, earlier, would have been a wiser strategy.

- The key supplements to the benefit package appear at this stage to be non-health services. Specifically, aspects of support that are granted inflexibly, if at all, in a fee-for-service setting--such as telephones and physical changes to homes--can be used to expedite management and improve access to care.

- An organization like HSCSN is likely to have many objectives in a demonstration like this, and public agencies should be comfortable with these different purposes, or explicit about any problems that they raise.

- Startup costs are unpredictable in any demonstration, and so they have been here, with costs totaling many times the level originally projected. Part of the problem is that the original projections were too optimistic about the startup time for the Demonstration--a message that echoes the lessons discussed at the end of Chapter 2. But the implementation of the model also turned out to involve far more systems and other developmental work than had originally been planned. While some of that work is a matter of judgment (see below), this experience is a reminder that new initiatives like this one should not assume the availability of systems and other supporting infrastructure.

- The particular expression of the model we see in this Demonstration is a fairly sophisticated one, notably in terms of the systems support being planned for care management. These systems are not *necessary* to case manage children with special needs--witness that, until late 1997 (when the new care management system was scheduled to go live), HSCSN was actively case managing using a Lotus Notes-based system. We do not doubt the limitations of that system. But in such areas as financial performance, care coordination, and selective utilization control, HSCSN has achieved the relatively successful results we have noted to date using that limited system. This experience serves to make the point that there are many different ways to manage care for this population, and that states thinking about replicating the Demonstration should consider what level of sophistication or elaboration they would like to establish. Our evaluation will have more to say on this issue once the new care management system is in place, and we are able to document its effects on the care management process.

- The introduction of managed care for a carved-out population, as in this Demonstration, raises extensive issues concerning how the Demonstration will be spliced into the intricate web of other systems and services. This Demonstration shows the difficulty of attempting to coordinate at the boundaries of contact with other systems. While there are important areas of progress in the District (the potential memorandum of understanding between CHCF and the Commission on Mental Health), there are also areas of almost complete failure so far (the schools). A small project on this scale is hard pressed to get the attention of agencies that have reasons not to collaborate.

These considerations will be substantially embellished, as the Demonstration matures and our evaluation accumulates more data on its implementation.

3.9 Future Areas of Investigation

Our work on the implementation of the Demonstration will continue throughout the evaluation. Key areas of data collection include:

- the evolution of HSCSN as an organization, including staffing, priorities, and financial performance.
- the implementation of the new care management system, with a particular emphasis on documenting how the system changes care management staffing, procedures, and accomplishments.
- financial performance, including documentation of risk-sharing calculations for all years, audited results for HSCSN for years after 1996, and areas of major cost savings against baseline data.
- the effects of personnel changes at HSCSN and CHCF.
- the developing understandings between HSCSN and related service systems, including Commission on Mental Health.
- certain key organizations we have not yet interviewed (notably, the District schools) to test the relatively one-sided information we now have on particular issues.

More generally, on most of these issues, we will want to bring in the findings that begin to accumulate from other areas of our evaluation, so that we can attempt to calibrate some of the effects being described to us in interviews (e.g., changes in utilization compared to baseline data, the effects of the new care management system, disenrollment rates over time, and survey results on parents' satisfaction).

3.10 Future Prospects: What Could Make a Difference?

In all of this data collection and analysis, it is essential to keep in mind how additional data could change our understandings. To that end, it will be useful to consider where additional information might have the most impact:

- The ambitious new care management system is designed to be far more effective (and more central to structuring care management decisions) than the limited, Lotus Notes system it replaces. It will be important to understand how the system changes staffing, patterns of care, access, and other aspects of operations, in order to understand the promise and problems of this approach to care management.

- To the extent that the collaboration between CHCF and HSCSN is due to the novelty of the initiative, we might see the development of more formal standards of monitoring as the District acquires more experience and the key issues are better understood. In any event, if any problems are revealed in the performance of the contractor, it will be important to reexamine the CHCF-HSCSN relationship to understand whether anything in that relationship contributed to the problems.

- If HSCSN did not continue to break even on a cash basis, our first-order confirmation of the practicality of the Demonstration, based on results to date, would have to be reconsidered.

- We would like to estimate the frequency and context of utilization of certain enhanced benefits in this Demonstration (e.g., telephones, residential modifications, and home care) to explore how much of any change in utilization is due to the expanded continuum of benefits being provided.

- The school system may have reasons for avoiding collaboration with the Demonstration that are critical to the Demonstration. Such information could change our understanding of how CHCF and HSCSN went about the work of coordination with other service systems.

- Additional focus groups with parents concerning the care management process will add a different perspective on HSCSN's care management than we have had to date, from interviews with providers and HSCSN staff.

- If our utilization analyses fail to confirm the changes in utilization being used to explain Demonstration savings, we would need to reexamine how HSCSN was able to save money.

At this point, there are an almost endless array of possibilities that could change our understandings of what happened here. The most important thing for us to do in the evaluation in the future is to bring findings from other components of the evaluation-including the utilization findings--to bear on the qualitative and process findings of the interviews, to begin to calibrate, qualify, and extend our understandings of the implementation process and its consequences.

4. CARE MANAGEMENT AND PROVIDERS

4.0 Introduction

The District of Columbia has developed and implemented a unique managed care demonstration for children who reside in the District and participate in the federally-funded SSI program. One of the innovative aspects of the Demonstration is its care management system. Each child in the Demonstration has a care manager, a primary care physician (PCP), and, as needed, a variety of specialty and allied health providers. As such, several providers participate in decisions and service provision that will impact on each child's care. As part of its evaluation of the Demonstration, Abt Associates seeks to understand:

- why and how providers participate in the Demonstration,
- how they interact with each other and with the children they serve,
- what decisions they make that might impact on quality of care and/or costs of care, and
- what impacts, if any, the Demonstration has on the practices of participating providers.

This report starts to address these issues by, first, describing the care management structure and process, as implemented by care managers in the employ of HSCSN, and then summarizing what has been learned to date about providers in the HSCSN network.

4.1 HSCSN Care Management

To learn about HSCSN care management, evaluators reviewed provider manuals and forms for assessment and referral; interviewed team leaders of care managers, the HSCSN medical director, the outreach director, and an assessor; and conducted four focus groups of care managers and care manager associates (these terms are defined below). All of these interviews were conducted in- person, using semi-structured protocols. A primary interest was to determine who made decisions that might impact on care and costs, and how those decisions are made. Not all of our questions have been answered at this stage, but much has been learned about the organization and operation of care management services at HSCSN.

4.1.1 Organization of Care Management

HSCSN care management employs an innovative staffing model that is designed to accommodate children with a variety of needs and levels of severity. Three care management teams are each lead by a senior, experienced health professional: one nurse, one clinical social worker, and one occupational therapist. Under each team leader, there are care managers who are experienced professionals, including nurses, social workers, and therapists--a mix of professions and experiences on each team. Under each team leader, there are also care manager associates, who have a B.A. and a variety of work experiences, including administrative jobs in health-related organizations. As of the writing of this report, there are three team leaders, seven care managers and twelve care manager associates. All three types of personnel are referred to as "care managers" by HSCSN staff, providers, and members' families. That convention is followed in this report.

Current HSCSN care managers have had varying amounts of formal instruction before working in the Demonstration, but all have been trained under a preceptorship lasting three-to-four weeks. This phase includes on-going instruction and guidance about: formal procedures, including authorization procedures; guidelines for providing care; and cost-related issues. The care management job is formally defined as:

- to assist in the access, promotion and maintenance of high quality care through the location, coordination, and evaluation of health services provided to members;
- to monitor delivery of health services to members for effective and efficient utilization;
- to assure that medical services are provided to members at the appropriate level of care;
- to assure that each member's individualized optimal health level is achieved and maintained;
- to facilitate access to all appropriate preventative health services; and
- to facilitate health education and community involvement activities that will empower families to become self-reliant.

Operationally, care managers authorize services. Providers need prior authorization from the care manager for any of the following services:

- transportation
- non-emergency ambulance services
- referral for consultation and specialty physician services not in the Plan of Treatment
- maternity care
- mental health services
- inpatient admissions
- same day surgeries
- MRIs and CT scans
- durable medical equipment
- urgent care visits
- home health services

The care managers follow guidelines developed for the authorization of each of these services by the HSCSN medical director and Quality Assurance Committee, as well as the American Academy of Pediatrics' standards of care and Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) guidelines. Care managers must secure approval of the medical director to authorize durable medical equipment (DME) over $2,500, hospital stays, and MRIs and CT scans. Care managers also review utilization of services accessed by members, consulting the medical director when there is a question about internally developed criteria being met.

In spite of the above job description, in focus group discussions, the care managers emphasized that the PCPs make the medical decisions. The PCP, they said, is "the driver of the bus." The PCP makes a decision and secures authorization from the care manager. While there was some discussion in the groups about how they "work for an insurance company," and what the significance of that may be, most care managers rejected the label of "gatekeeper." Care managers described their role as one of "facilitator," to address the needs of members and their families and to assist providers. Disagreements with providers' service requests are addressed with information about the criteria applied and the rationale behind them. While the evaluators have not been able to examine this issue in HSCSN records, interviews of parties in all relevant categories suggest that there have been very few denials of services that have been requested by providers.

Care managers at all levels--even those with very specialized training--emphasize the multiple non-medical needs of most members' families and the importance of addressing these so that the child can benefit from a stable home environment. They spend much of their time educating families about, and helping them use, appropriate sources of health care. Care managers believe that the children who can benefit most from the HSCSN care management program are not necessarily the most medically complex, but those who have multiple needs, including behavior problems. Care managers do not expect PCPs to get involved in these non-medical issues (although some occasionally do); rather, they see such involvement as their own special role in the HSCSN program.

4.1.2 Determination of Caseloads

Assessments of new members are reviewed at meetings of each of the three teams, during which each new member is assigned for care management. The criteria for assignment are level of medical acuity, and type and complexity of service needs. The most complex are assigned to the team leaders: the most medically complex members to the nurse, the most serious mental health problems to the social worker, and children with the most serious functional problems or rehabilitative needs to the therapist. The team leaders, who handle the most complex needs, have the smallest caseloads, ranging from 35-40. A child in the mid-range in terms of acuity would be assigned to a care manager, and, again, the specialty of the care manager would be matched to the needs of the child: for example, a child who uses a feeding tube would be assigned to a nurse, and a child with behavior problems would be assigned to a social worker. Caseloads at this level range from 50-80. A child with less severe problems would be assigned to a care manager associate. Caseloads at this level range from 90-140.

All three types of personnel emphasize that they perform the same job. Differences between the levels of care management are: the more acute the children's conditions, the more experienced the care manager; and the more complex the children's needs, the smaller the caseloads of the care managers. Matching the more acute children's needs to the professional training of a care manager is intended to ensure that the children's needs are understood, and to facilitate communication between the care manager and the children's providers.

Each child and his/her family work with one care manager, but within HSCSN the care managers emphasize that they work in teams. Within each team there is frequent consultation with the team leader and among care managers across professional specialties and acuity levels. Each team meets weekly to formally review cases. These meetings provide opportunities to note changes in the children's needs and sometimes a change in acuity level. The latter may lead to a change in care manager assignment, which is coordinated by the outgoing and incoming care managers to be minimally disruptive to the child and family.

4.1.3 Connections to Assessment and Outreach

Assessment. Earlier in the Demonstration, some of the current care managers conducted assessments, but as caseloads grew it became necessary to use separate assessors, who are usually contracted for that task.[37] It is the expectation of the care managers that assessors will have a health care background. Assessments cover medical diagnoses and non-medical problems. They are done in the home, and there is no requirement that the child be present. Often the child is in school.[38] The assessments are therefore based largely on self-report by parents and guardians. Care managers are concerned about the accuracy of this process and have noted some problems. Parents and guardians sometimes convey incorrect information about diagnoses. Often they do not know or understand enough to provide accurate answers. Some of their responses convey unrealistic expectations: for example, some parents use the term "developmental delay" for conditions that are permanent rather than temporary.

Care managers must develop a plan of treatment (PoT) based on an assessment, but, recognizing the limitations of the assessment process, they consider the PoT to be a living document from the start, to be revised when more information is learned by the care manager and when the PCP has examined the child. A completed PoT includes goals, prescribed services and planned care manager activities for: preventive care; nutrition; functional skills; education/vocation; and support/education for member,

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[37] We have recently become aware of another change in the personnel conducting the assessments from contracted staff with clinical backgrounds to HSCSN outreach staff who may or may not have clinical training.

[38] Assessments are conducted during daylight hours as some DC neighborhoods are considered unsafe at night.

family, and caregivers. PCPs may receive PoTs in advance of medical records. When evaluators interviewed PCPs, they were found to be less bothered by the weaknesses of the assessment and PoT development process than the care managers. PCPs generally said that the PoTs were a good start and provided more information than they often had about a child. Because of time constraints of the enrollment and assessment process, PCPs were sometimes asked to agree to authorization of a service before they had seen the child, and some objected to doing this.

Outreach. Outreach workers have a role in recruitment and orientation of members, and subsequent to recruitment they provide services to support the care management role. Outreach workers, who know the communities in which the members live, assist primarily with services to improve compliance and services to fulfill the many non-medical needs of members and their families. The latter may include food, clothing, housing, and legal assistance. A Request for Outreach Form can be used by care managers to secure outreach services for any of the following reasons:

- broken appointments
- locating members for medical care and EPSDT
- reorientation regarding benefits and procedures
- impending termination of eligibility for SSI benefits
- retrieving information such as signatures on documents
- identifying community resources.

Earlier in the Demonstration, care managers more often made direct referrals to community resources, but as caseloads grew, the more specialized outreach role developed. Care managers may still make such referrals and direct contacts if they wish, and occasionally some do--particularly if a complex situation must be described to the community agency--but active caseloads often make it difficult for them to do that. Care managers still focus on compliance issues by making appointments when caregivers cannot make them, following up with providers to see that appointments are kept, and educating members and families as to the importance of keeping appointments and reasons for seeing PCPs rather than using emergency rooms for every medical need.

4.1.4 Interactions with Providers

Care managers interact with providers by telephone, mail, and fax regarding appointments, referrals, follow-up, and a variety of issues that impact on the child's care. The most formal processes are the securing of PCP signatures on PoTs, subsequent interactions concerning modification of the PoTs, the authorization of services (discussed above), and the referral process. To make a referral, PCPs should complete the referral section of HSCSN's Encounter/Referral Form and fax it to the Care Management Department. Or, the PCP can call and have the care manager complete the referral form. When referral forms are sent to specialty providers, they include date limitations of the referral, services or procedures authorized, and number of visits authorized. After a consultation, the completed encounter forms are submitted to HSCSN, and a copy is sent to the PCP.

Most PCPs who were interviewed found the referral process quick and efficient and did not find it problematic when the care manager selected the specific specialty provider from the HSCSN roster (the PCP would have specified the type of provider/service needed). (Issues that were raised about this process by PCPs at Children's National Medical Center are discussed in a subsequent section.) In practice, there are deviations from the formal procedure. Many children already had long-standing relationships with physician specialists, therapists, and DME providers at the time that they enrolled, and their families might try to bypass the referral process. In these cases, if the service is specified in the PoT, and if the provider is in HSCSN's network, the provider would only have to backtrack the paperwork. If the provider is not in the network, HSCSN would be likely to try to recruit him/her. If the service is not specified in the PoT, the PCP and care manager determine if the service should be provided; if so, the formal referral process is implemented.

There is a lot of variation in the ways that providers communicate with care managers. Some PCPs were in the habit of discussing their HSCSN patients with care managers. These knew the names of the care managers, knew what services they performed, and generally found them helpful. Several commented that it was useful to have a person who "knew the child and the family" and had a comprehensive view of their needs. Most PCPs did not know how the HSCSN care management program was structured or how children were assigned to care managers, but they usually found the care managers to be sufficiently knowledgeable about the children's medical needs. Evaluators heard occasional negative comments about particular care managers, but these appeared to be temporary personnel issues that HSCSN was addressing, not systemic problems with the care management process.

Among the providers who communicated directly with the care managers, most thought that the care management system helped to achieve greater compliance among the HSCSN enrollees than is common among Medicaid patients. Other providers assigned some or all of the communication with care managers to a nurse or an office assistant. When interviewed, these personnel made the same favorable observations.

The pattern of communication was different for most specialists, especially for those who see a patient only short-term. These had minimal contact with the care manager and were often doubtful that HSCSN was achieving the stated objectives of addressing comprehensive needs and increasing compliance. One psychiatrist disliked being called upon for short-term consultations--usually when medication was needed--while cheaper mental health providers were used for long-term therapy. This physician's skepticism included questioning the quality of the primary care that was being provided to the children (and this was a rare criticism).

Some larger specialty practices had designated a nurse or office assistant to communicate with the care managers. These generally had favorable comments to make about HSCSN and the work of the care managers. One nurse commented that she could not recall so many children with special needs being referred to her specialty practice. She thought such children were often not screened to see if they needed this particular service, and that the care managers ensured that such screening was done under the HSCSN program. Larger specialty practices also reported more attention and follow-up from other personnel at HSCSN than was reported by smaller specialty practices.

There was notable agreement among care managers and providers that the speed of the HSCSN authorization process had an especially favorable impact on the timely provision of DME. One DME provider pointed out that braces and other equipment have to be customized to fit growing children. The authorization process for conventional Medicaid coverage could take so long that in the time elapsed the child could grow sufficiently to require a new fitting for the needed equipment. That the HSCSN authorization process for equipment under $2,500 could be completed in a couple of days was considered by many to be an important advantage of enrollment.

The general trend found in our interviews was: the more frequent the contact between provider (or provider's employee) and care managers, the more favorably impressed the provider would be with the care management system and HSCSN services overall. Provider responses to the Demonstration will be elaborated in sections to follow.

4.1.5 Interactions with Clients/Families

Some care managers expressed regret that they rarely have in-person meetings with members and their families. Such meetings in their offices are infrequent, meetings in members' homes even less frequent. This is viewed as one of the constraints of "working for an insurance company" in a cost-conscious environment. Nevertheless care managers spend much of their time interacting with families and guardians of enrollees by telephone. They sometimes make appointments for members, they provide transportation to appointments when needed, they authorize the services provided by the outreach department and other supportive services such as respite care.

Much of care managers' communication with members' families and guardians is intended to support them through crises and to educate them in the proper way to use health services, e.g., not to use the emergency room for non-emergencies, and the importance of preventive and primary care. As is common for care managers in many programs, they have to stop short of creating dependency on them and on the supportive services. Therefore they emphasize the role of educating and "empowering" the families to eventually manage their problems by themselves. This goal is consistent with the cost-containment objectives of a managed care organization; it therefore provides an ideological resolution to the conflict of advocating for children versus "working for an insurance company." Many of the care managers have previously worked in health care organizations that resolved this possible conflict in a similar way.

Apart from the emphasis on educating and facilitating, there are also many home situations that are problematic and urgent, sometimes involving abuse or neglect. These need to be addressed and stabilized to ensure that the enrolled child or children can receive and benefit from medical care. Care managers' involvement with members' families often includes working with court systems and child protective services as well as some communication with the school system.

The assignment of different severity levels to different care managers, and the corresponding adjustment of caseloads, appears to maximize the possibility that care managers will have time for the members and families that need their attention. At any given time, much of a caseload will be inactive. If the proportion requiring active intervention increases, the team system enables the care manager to rapidly secure assistance and to shift caseloads to a manageable level. The goal is for families to get attention when it is truly needed, and for families to become more independent and able to manage for themselves as time goes on. The system is not intended to have sufficient slack to support extensive "hand-holding" or to create dependency on supportive services.

One physician interviewed for this study questioned whether so much emphasis on care management would be necessary if the school system was "doing its job" for children with special health care needs. Based on what the evaluators currently know about services in the Washington D.C. school system, it is unlikely that they could provide services currently authorized by HSCSN care managers. A therapist who had recently worked for the school system, and is currently in the HSCSN network, commented that her work had been severely limited in the school system because that system addressed only educational goals and would only provide services that facilitated learning and classroom performance. For example, a child with cerebral palsy and severe cognitive deficits is not likely to receive, through the school system, any therapy to improve muscular and other clinical problems. It is also unlikely that many non-medical services provided by the care manager would be considered to be related to educational goals and therefore addressed by the school system.

4.1.6 Parent Reaction

Currently, little is known about parent reaction to the Demonstration's care management system. While a series of focus groups have been conducted with parents, they were designed to capture parents' views of HSCSN efforts in marketing, recruitment, enrollment and assessment. Therefore, little data were gathered about parents' perception of the care management services. This topic will be explored in greater detail during latter focus groups. From the few comments that were made about care management, it appears that parents are generally pleased with the arrangement. Parents are particularly appreciative of the service coordination aspect. Prior to enrolling their children in HSCSN, many parents were frustrated at the time and effort they had to expend, often unsuccessfully, to coordinate services for their children. Therefore, the overwhelming sentiment expressed is that service coordination has greatly relieved them of a burdensome task.

Parents were most impressed by the caring attitude of the care managers toward their clients. Several mentioned the care managers' willingness to make hospital visits, to facilitate parents' discussions with advocates for children with special health needs, and to provide assistance with other non-medical matters as evidence that care management is an important and much appreciated service. Before enrolling their children in HSCSN, parents were often forced to place emphasis on clinical services because those were viewed as absolutely essential for their children's health and well being. As a result, many of the psychosocial needs of the child and the family were neglected or handled in a haphazard manner. HSCSN care management, according to some of the parents, addresses a comprehensive range of needs, and thus has resulted in a more equitable balance between medical and non-medical services.

4.2 HSCSN Provider Network

Prior to completing this report, we interviewed HSCSN providers, in these categories:

3	hospitals
2	clinics
4	group primary care practices
7	individual PCPs
5	physician specialty practices
3	non-physician providers of mental health services
2	DME/supplies
1	physical therapist
1	occupational therapist
1	dentist.

We chose these providers by first sampling children who could be categorized as follows:

- average users of services;
- users of mental health services;
- above-average users of medical services (but not ancillary services); and
- intense users, including ancillary services.

We then sampled the providers listed for these members, filling quotas for various provider categories. The goal was to ensure that sampled providers include specialty physicians, mental health professionals, physical and other therapists, as well as primary care physicians. The interviews began with a semi-structured protocol that addressed recruitment and participation decisions, care management, program experiences, and provider satisfaction. As key issues became apparent, and the types of individuals to be interviewed increased, the content was revised.

Eleven of the interviews were conducted in person, the remainder by telephone. In some cases, we spoke to both a physician and a nurse or office worker who had frequent interaction with care managers. In two cases, both physician specialty practices, we interviewed only a nurse or care manager employed by the practice as these individuals managed the contacts with care managers, and physicians in these practices were unaware of which children were covered by HSCSN. In many cases, we spoke to a business or financial manager in addition to health care providers, as the latter were often not aware of rates and other business issues. Some of the group practices were in hospitals, and in hospitals that served many HSCSN children we interviewed both hospital managers and physician practice managers. While the number of institutions, practices, and providers interviewed is not large, several hundred HSCSN children are served by these institutions and providers.

We also reviewed HSCSN physician and provider manuals, credentialing requirements, and physician participation agreements, and interviewed the HSCSN medical director, the former vice president of provider affairs, and the provider relations staff regarding recruitment and HSCSN interactions with providers.

4.2.1 Recruitment: HSCSN Implementation and Provider Response

Many providers in HSCSN's network were recruited through the personal contacts of the former vice president for provider affairs and the current medical director. Others were either approached by HSCSN, or they applied to HSCSN themselves, when children that they previously cared for under the Medicaid program were enrolled in the Demonstration. Still other providers were recruited to complete the range of services that the medical director deemed necessary for the enrolled population. The hope was that children who had regular physicians and other providers prior to enrollment would be able to continue with those providers in the HSCSN network. The providers interviewed for this report verified many cases in which this had happened.

Criteria for recruitment included coverage of the geographical areas in which the children were located, as well as professional standards such as, for physicians, board certification and hospital admitting privileges (or an arrangement with another physician regarding admitting privileges). Having providers in the network who are culturally competent to serve the population was another consideration. HSCSN appears to have been particularly successful in recruiting African-American providers. Hispanic providers are also represented, but appear to be in shorter supply in the District of Columbia.

Mental health providers willing to serve the Medicaid population also appear to be in short supply in The District. Part of the problem may be related to District rules that therapists and counselors who are not M.D.s cannot be paid by the conventional Medicaid program unless they work for freestanding mental health clinics that have a psychiatrist on staff and satisfy other requirements. HSCSN has been able to include some of these providers in their network, as linking them with psychiatric and other services is not a problem, given the structure of the Demonstration. Even so, there appear to be more mental health issues among the enrolled population than expected--

this has been stated by both HSCSN staff and participating physicians--and the need for community-based providers has probably not been fully addressed. It is also necessary for HSCSN to contract with out-of-state residential facilities to obtain some mental health treatment for its members. In some cases, described by care managers, enrollees have been brought back from out-of-state residential facilities and provided with community-based treatment and supportive services. Thus far, the care managers believe these arrangements have been beneficial to the enrollees as well as less costly for the program.

In recruiting providers, a strong selling point was the care management program. Some physicians had been reluctant to serve Medicaid patients and many had been unwilling to increase their Medicaid caseloads. They were concerned that the time required for physicians' office personnel to contact families and follow up on appointments to increase compliance, and to address urgent non-medical needs that interfered with their medical treatment, could not possibly be covered by Medicaid reimbursement. HSCSN offered them a care manager to address these needs.

In most cases, HSCSN offered better rates than conventional Medicaid, although some smaller specialty providers that we spoke to claim that this was not the case. Some complained that rates were still too low, even though they were higher than those of conventional Medicaid. One primary care physician who had a very large practice of mostly Medicaid-funded patients said that he would prefer that HSCSN capitated him so that he could "rely" on the income. HSCSN also had intended to reimburse PCPs for some interactions with care managers, but there appears to be a lot of confusion about this, and it is not clear if many PCPs are sufficiently well-informed to know how to bill for this payment. Evaluators have not found a description of this policy, or the billing procedure in the HSCSN Physician Manual. HSCSN also promised timely payment. Most providers we spoke to found that they delivered on this promise, although some noted a few delays and problems at the beginning of their participation. Others commented that they had not had a serious problem with timeliness of conventional Medicaid payments, but that the regular Medicaid program often made mistakes in payments (resulting from inaccurate entering of codes) and these could take months to correct. No provider reported that problem with HSCSN.

During recruitment, HSCSN was accommodating to many provider requests, particularly regarding the number of members they wanted to treat. Some joined to keep their patients who were joining HSCSN, and they did not want any additional patients. Others joined because they wanted more patients. Providers often noted that HSCSN was going to be the "only game in town" if they wanted to serve children with special needs in the Medicaid population. Because of this, some felt they had no choice, but noted that they appreciated the way HSCSN approached them--offering enticements (regarding rates) and accommodations (regarding number of old/new patients they would serve) as if they had a choice and their participation would be valued.

The Provider Relations Department of HSCSN offers training to network participants and their staffs, primarily to explain HSCSN procedures and billing practices. Provider Relations also expects to contact participating institutions and providers periodically, but feedback from providers suggests that this is not done consistently.

4.2.2 Provider Experience: Current Practice and Possible Outcomes

Provider Satisfaction. In general, PCPs in the network are more satisfied than physician specialists, for several reasons. First, providers who have more contact with the care managers, and with HSCSN in general, tend to be more satisfied. As discussed above, the care management process requires frequent contact between the care manager and the PCP, or at least with the PCP's office. In most cases, this seems sensible because the PCP has much more contact with, and a broader range of responsibilities for, the child. However, some children also see a specialist regularly, and the formal process does not require more interaction with the care manager for these specialists. In addition to having less communication with care managers, specialists claim to be less frequently contacted by HSCSN, and sometimes they claim to have negotiated less favorable rates and working arrangements with HSCSN than the PCPs.[39]

Some physician specialists also complain about lack of contact with the PCPs. Many seem to feel generally "out of the loop," and not part of the team. After hearing this problem stated by specialists, evaluators probed more about PCP/specialist contact when interviewing PCPs. Some PCPs spoke of frequent telephone contact with specialists, but in these cases the specialists had made the first call. Our conclusion is that most PCPs are receptive to contact with specialists, but unless a specialist makes the first call, the system does not encourage such contact.

Another reason for less enthusiastic responses of specialists is that HSCSN follows the by-now customary managed care strategy of encouraging prevention and primary care while looking for opportunities to decrease--or at least control more closely--the use of expensive specialty services. A typical example is the psychiatrist who maintains that he is only used for prescriptions while less expensive mental health practitioners provide on-going care, and some behavioral issues that he might want to address are handled by the PCP.

The perceptions of specialists are clearly different from those of PCPs, as some specialists quickly conclude that PCPs have "more to gain" from the HSCSN approach. That some PCPs refer to the HSCSN program as "the only game in town" if one wants to serve this population, reinforces the perceptions of some specialists that PCPs are anxious to please HSCSN, and therefore some of their care decisions may be suspect. These perceptions are not conducive to team building, and there do not seem to be any system requirements or incentives for team interaction beyond care manager/PCP contact.

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[39] On these issues, the evaluators are limited to self-reported data, and we present these as evidence of problematic perceptions rather than as evidence of documented problems.

Provider Perceptions of Care. While we have heard some assertions of poor care being delivered (some of these have been noted in previous sections), these have not been immediately verifiable, nor have they been consistent enough to lead us to predict that other parts of this evaluation will reveal that the care provided by HSCSN is inadequate. Assertions of poor care invariably come from specialists. When PCPs have complaints they are usually about procedural issues.

When providers were interviewed, if they had experience with conventional Medicaid, they were asked to compare care delivered in the conventional Medicaid program with care delivered by HSCSN. Most providers believed that HSCSN delivered more primary care and did a better job of screening children. If providers interviewed had experience with other managed care organizations, they were asked to compare care delivered by those organizations with care delivered by HSCSN. In most cases, HSCSN was said to be comparable or better. Some favorable comments were that "other" managed care plans are more likely to question prescriptions, and "other" managed care plans do not understand (as HSCSN does) that older children with developmental problems may still need more costly pediatric radiology services.[40]

All interviewees were asked about utilization review by HSCSN and any denials of services that were requested. There were a couple of complaints about the HSCSN rule that competitive bids must be obtained for DME items over $2,500, but generally the speed of DME provision, as described above, was considered excellent. In view of the hundreds of children served by these providers--and many of the providers have been with HSCSN since the beginning of the Demonstration--there were surprisingly few instances in which requests for a service had been challenged, much less denied. One denial of service that was described to us--involving a request for cosmetic surgery to address self-esteem issues--had left both a PCP and a specialist with a negative impression of HSCSN.

Institutional Issues. Problems surfaced at two major Washington D.C. institutions that are in the HSCSN provider network. First, prior to the Demonstration, D.C. General Hospital took over from the District a group of public health clinics. In doing so, D.C. General inherited a low Medicaid rate for those clinics, as the District had excluded the State portion of the Medicaid payment because the "state" could not pay itself when those clinics were run by the District. HSCSN attempted to include those clinics in their network, but ended this effort when the unionized providers in them refused to allow their credentials to be examined. Nevertheless, top management at D.C. General seems to blame HSCSN for some of this history and told the evaluators that the hospital (which has a different Medicaid rate history and has not had a credentialing problem) does not have a contract with HSCSN. The hospital does in fact have a contract with HSCSN and some claims have been filed, although it is not clear if D.C. General has been billing HSCSN consistently. At the provider level, HSCSN appears to have a good working relationship with a D.C. General clinic (not one of the former public health clinics) that provides services to children with special needs. It would seem to be in

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[40] HSCSN also fared well on "red tape" and payment issues in comparison with conventional Medicaid and with other managed care organizations.

HSCSN's interest to resolve old issues with D.C. General management, as the hospital is a major health care provider for poor children in the District.

Children's National Medical Center is the other institution at which problems surfaced. Initially, we interviewed at the management level at Children's, where we found general satisfaction, but perhaps less follow-up (at the management level) from HSCSN than would be ideal. We also interviewed employees of two Children's physician specialty practices, who had extensive contact with HSCSN care managers, and we heard positive comments from them. Finally, we talked to the physicians who facilitate the primary care services provided to HSCSN by Children's, and there we heard about a number of problems. In a November 1997 roster, available to the evaluators, Children's provided primary care for 491 children representing approximately 26% of the children in the Demonstration. Problems noted at this institution are therefore important, even if they contrast sharply with what we have heard from other organizations providing PCPs to HSCSN.

Because of the large volume, Children's insists on assigning PCPs to the enrollees so that they can distribute the workload reasonably. A senior physician receives information from HSCSN and makes the assignments. The physician's only HSCSN contact appears to be an administrative person, and the flow of paperwork appears to be uneven. The physician maintains that there are delays in sending information and some omissions; most notably she says that she rarely receives a roster of HSCSN children assigned to Children's. However, several other problems noted appear more critical.

Primary care physicians at Children's say they have less nursing support and fewer administrative personnel than the specialists at Children's. They therefore have to communicate personally with the HSCSN care manager, and, given the large volume, they say, they spend a lot of time playing "phone tag" and rarely reach a care manager.[41] They believe that HSCSN should provide at least a part-time on-site care manager at Children's. This may or may not be a good solution for HSCSN, but the Children's PCPs feel strongly that the possibility has to be seriously entertained.

They would also like all authorizations to be made by the PCPs, not by the HSCSN care managers. The physicians we spoke to did not address the issue of sharing risk, nor have they discussed this with Children's management, which is likely to be more sensitive to the issue of linking authorization decisions to the assumption of risk. The Children's PCPs also have noticed that some HSCSN care managers want to authorize visits to specialists (often outside of Children's) that members visited prior to enrolling in HSCSN. They believe that many of these conditions could be monitored successfully by PCPs at Children's. They also object to requiring members to use an HSCSN after-hours call number, rather than a Children's after-hours call number, if the PCP is at Children's. In one case, they objected to HSCSN using urgent care services of another hospital for a member assigned to a Children's PCP (they believe the other hospital had

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[41] We had not heard this complaint from any other provider, but the Children's circumstances are unique.

negotiated cheaper rates for urgent care services). In effect, the Children's PCPs believe they have most necessary services under their own roof, and they want to function in a manner that would approximate a staff-model HMO; while HSCSN is asking them to be part of a larger network and to follow rules designed for a dispersed network of providers.

It is unlikely that HSCSN can satisfy all of these demands, but the evaluators believe it is equally unlikely that HSCSN would be unwilling to negotiate some of the issues with a provider that is so important to the Demonstration. The Children's PCPs claim they have had little contact with the medical director or others at HSCSN, and as little contact with their own management, which negotiated the current contract. Notably, the Children's PCPs have no complaints about denial of services or any other quality issues in their dealings with HSCSN, but their perspective on how primary care at Children's should be handled is radically different from that of HSCSN.

The evaluators discussed the Children's PCPs' issues with HSCSN's medical director, who responded to several specific points in the following way: (1) The HSCSN medical director maintains that she has been meeting with Children's management and/or staff every 1-2 months. (2) HSCSN has tried several times to negotiate urgent care rates with Children's, but the hospital continues to charge emergency room rates for urgent care. (3) Families with PCPs at Children's can use the Children's after-hours number, but many prefer to use the HSCSN response line. (4) HSCSN staff have had as much difficulty reaching Children's PCPs as the PCPs have had trying to reach HSCSN care managers; the medical director has offered to have a care manager spend some time at Children's and some time at the other teaching hospitals in the network, but maintains that Children's found this proposal unacceptable. There also appears to be less administrative support at Children's for PCPs, as opposed to specialists, which exacerbates the communication problem and suggests a less-than-ideal structure for participating in a managed care network. In general, there appears to be some awkward history between Children's and HSCSN, including early opposition of a senior Children's PCP to the idea of managed care for children with special health care needs.

4.3 Considerations for Other States and Interested Entities

Reviewing what has been learned from the study of care management and providers in the Demonstration, thus far, there are some quibbles and squabbles among providers--and the issues at Children's National Medical Center might even threaten the viability of the Demonstration if they are not addressed--but there are no serious alarms that suggest the care of the children is being compromised. It is even possible that the care management program may have a positive impact on health outcomes if it genuinely overcomes service fragmentation, promotes primary care, and helps to resolve non-medical issues that threaten to compromise the delivery of care. The speed of authorization of DME may be particularly beneficial to some children.

The care management approach employed by HSCSN is innovative and bears watching as a model that might be worthy of replication by the end of the Demonstration. It has structured, but not overly-complex, criteria for sorting cases by acuity level and type of need. HSCSN also appears to have appropriate staffing for those levels and needs. The team process provides a mechanism for cross-fertilization of skills and knowledge among care managers, as well as a mechanism for assessing the changing needs and acuity levels of enrollees. The process also seems to identify the need for changes in caseloads before care managers become overburdened with too many members having medical and other crises. A major focus of the care management work--to encourage eventual independence of the families--is consistent with the cost containment objectives of HSCSN, which suggests that care managers, who usually view themselves as advocates for patients, may have few ideological conflicts with the goals of this managed care organization.

The decision to have separate outreach workers find and provide non-medical services also appears to be a sound one for the care management system. The care managers can focus on working with the family and providers, rather than trying to find and secure services.

The process employed by HSCSN in recruiting providers also appears to have been successful. Having key individuals in the organization--including the medical director-with extensive provider contacts in the area was critical. Particularly notable in our interviews with providers who joined is that they felt courted and valued by HSCSN even when they felt they had little choice but to join the provider network. The initial training offered to provider's offices was also appreciated, although perhaps was not sufficient in every case. Some issues raised during our recent interviews highlight the importance of maintaining communication with providers throughout the implementation of the program.

As to aspirations of States to emulate what is being done by HSCSN, it is important to remember some key characteristics of the District's environment. For example, while it might not be reasonable to expect a school system to do all the care coordination, as suggested by one physician, it is reasonable to anticipate that a school system in another state might do more than the D.C. school system. Also, each State has its own Medicaid history, and a new Medicaid program has to address some of the problems that providers have had in that State, which may differ from the D.C. experience. Equally important, the extent of managed care penetration and the reputation of managed care in each State will have varying impacts on providers' expectations for the new program.

4.4 Future Areas of Investigation

While there appear to be many positive aspects to the care coordination features of the Demonstration, a question that cannot yet be addressed is: Does it have any impact on the costs of care and quality? Looking at the care management and provider interview data, it is not clear that it will, or how that might happen. The authorization of services by care managers was objected to by PCPs at Children's, but in most cases in the Demonstration it seems clear that the PCPs are indeed driving the medical decisions. However, they receive fee-for-service payments and have no financial incentives to contain costs. Nor do they receive the extensive training on authorization and cost issues that the care managers receive.

Are the care managers quietly indoctrinating the PCPs? That is unlikely, especially since many PCPs delegate communication with the care manager to another person in the office. The major leverage with PCPs at this point is that HSCSN is the only insurer in this program. Willingness to please and continuing to work with HSCSN is not sufficient reason to think that physicians can make cost-effective decisions. Most of the PCPs interviewed had little past experience with managed care, and they do not discuss cost containment as one of their responsibilities. At this point, some physician specialists seem to believe that cost containment efforts are targeting them, but there is not strong evidence of that, and the issues at Children's suggest otherwise.[42] In addition, because providers are paid on a fee-for-service basis, they face few financial incentives to follow cost containment strategies.

The current belief at HSCSN appears to be that an emphasis on primary care, coordination of services, and supportive services, with close review of the most expensive services, will be cost-effective in the long term. If that approach works, how will it work? Among the possible explanations are:

- Children who formerly received no regular primary care will make fewer visits to the emergency room and have fewer acute episodes.
- Coordination of care will avoid duplication of services and the provision of unnecessary services.
- Improved knowledge of a member's needs, gained from monitoring, will lead to the provision of more appropriate services.
- Provision of supportive services, and resolution of non-medical issues, will enable the member to get the maximum benefit from medical care.

Other possible explanations can be derived from HSCSN's care management objectives and from knowledge of other care management programs, but it would be difficult to come up with an explanation for this Demonstration that would reference provider incentives to reduce spending in a significant way.

Operationally, we need to follow up with providers later in the Demonstration, and, over time, to try to determine the ways in which they may be having an impact on

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[42] Although specialist-to-specialist referrals are not allowed, and this rule is intended to address both fragmentation of services and goals of cost-containment.

service delivery, health outcomes, and costs. We also need to observe changes in the care management program and care management staff as they evolve over time.

4.5 Future Prospects: What Could Make a Difference?

The basic care management system appears to be stable and well-designed for this Demonstration. As discussed above, it could ultimately have an impact on care, but it is not as apparent that it will have an impact on reducing costs. Not all provider arrangements are as stable as one might expect at the moment. The issues at Children's could have serious consequences if they are not resolved, given the importance of that institution in the Demonstration. Outside of Children's, specialty provider issues noted are not unusual in a managed care program. They are probably not threatening to the program, but could be addressed. In general, communication with providers, and how providers articulate with care managers can be worked on.

Concerning providers, arguably the change that could make the most difference would be if HSCSN initiated risk-sharing arrangements with providers. This would address concerns about incentivizing providers, but decision making strategies might have to be reexamined. Whether or not the PCPs have "really" been making the medical decisions all along, would become an active issue, as would any inclination on their part to make different decisions when their incentives are changed.

Lastly, any change in direction at HSCSN should be evident in the care management program and in the ways that care managers interact with providers. For example, a more explicit focus on cost containment might immediately impact on the way that care managers spend their time and on the services they authorize.

5. OUTREACH AND ENROLLMENT

5.0 Introduction

The operational phase of the District of Columbia's 1115(a) waiver for a managed care demonstration for children in the Supplemental Security Income (SSI) program began on December 15, 1995. On that date, the District's Medicaid office, the Commission on Health Care Finance (CHCF), mailed enrollment materials for this voluntary program to 500 children. Two months later, in February 1996, the first eight children began receiving services from Health Services for Children with Special Needs (HSCSN), the non-profit health plan operating the District's Demonstration. As of November 1, 1997, monthly enrollment stood at 1,901 children, representing about 71% of eligible children that can be located. During the 22 months of operation, the Demonstration has served a total of 2,089 different children and has experienced a total of 26,286 member months.

At 71% of located children, Demonstration enrollment appears to be very successful. However, achieving this success has not been easy. The most important problem faced by the District and HSCSN has been identifying and locating a large proportion of the population believed to be eligible for program services. In addition, the initial enrollment materials have not been particularly effective in eliciting enrollment, consequently during the planning phase, the District and HSCSN had not fully anticipated the amount of time and resources necessary to market the program. Now during a period of stable enrollment, HSCSN views the enrollment process as manageable, but unexpectedly problematic.

Using enrollment data maintained by HSCSN and oral history obtained through site visits to HSCSN and the District in April and September 1997, this report provides a history of the Demonstration's enrollment experience up to November 1, 1997. One issue that this report is not able to address is selection bias. Because the Demonstration is voluntary, it presents an important opportunity to study who chooses to take-up such a program. As this report is being written, diagnostic information and information about utilization and costs are not available for those not taking up demonstration services so that very little is known about those children not in the Demonstration.

After briefly describing the enrollment process, the results of each aspect of that process are discussed. Section 5.3 discusses the Demonstration's enrollment experience while Section 5.4 describes the children who were enrolled as of November 1, 1997 and those who have disenrolled. This chapter closes with a discussions of lessons learned to-date, considerations for future research, and what kinds of events could alter the results that have been seen so far.

5.1 The Enrollment Process

In the Fall of 1993, the originator of the idea for the Demonstration, conceived enrollment as a simple process--all children in the District's SSI program would be automatically enrolled in the Demonstration when operational status was achieved. However, from the point of view of the health plan operating the Demonstration, HSCSN, the enrollment process has been unexpectedly problematic, but manageable. Instead of a one-step automatic enrollment of all eligible children, the current enrollment process involves three distinct steps and families have the option to decline at any point in the process. As such, the enrollment process is designed to allow families to have choices and to diminish some of the marketing abuses noted in other Medicaid waiver programs (e.g., The New York program as reported by Sparer and Chu, 1996).

In the District's Demonstration there are three steps in the enrollment process:

1. **Outreach and Selection of Demonstration Services.** As discussed below in section 5.1.1 and section 5.1.2, families are notified that their child in the SSI program is eligible for a managed care health plan designed specifically for the child, and the family decides whether or not to enroll the child;

2. **HSCSN's Health Assessment of Prospective Participants.** For those choosing to enroll in the Demonstration, HSCSN must conduct an extensive in-home health assessment which collects an inventory of information about the child's health status, needs for a variety of medical and social services, and environmental information such as the quality of the child's housing (discussed more fully below in section 5.2); and

3. **Enrollment.** After the health assessment has been completed, and HSCSN has verified the child's SSI eligibility, the child is enrolled and begins receiving services through HSCSN's plan. Enrollment results are presented in section 5.3 and section 5.4 below.

5.1.1 The District's Mailing

The enrollment process begins when the District's Medicaid office, CHCF, mails out an enrollment packet to the parents of eligible children. As of November 1, 1997, the District has mailed in excess of 4,450 packets. Before an enrollment packet can be mailed, the District must first identify eligible children. This identification process has primarily relied on the use of Medicaid and other program participation records maintained by District offices. A prospective system to identify new SSI beneficiaries upon entry into that program has not been established.

The enrollment packet is sent out in a large 9 x 12 inch envelope stating "Important Information About your Child's Health Care!" on the front. On the back in seven different languages (four of which are Asian languages) the recipient is instructed to have the enclosed information translated immediately. Enclosed in the envelope are five pieces of information.

1. A letter from the Commissioner for CHCF explaining that the program is voluntary and that the family has 45 days to make a choice.

2. A one-page Selection Form and a postage paid envelope.

3. The District's 12 page description of the Demonstration and what managed care means for the family.

4. HSCSN's member booklet which describes the enrollment process, services, scheduling of appointments, how emergencies are handled, and a listing of services available through "the NET" (the name of the plan).

5. A listing of providers in HSCSN's network.

Families have 45 days to return the selection form to CHCF. If the selection form is not returned within that window, HSCSN is allowed to directly market the program to the family. The response to the mailings has been poor. Slightly less than 20 percent of those contacted responded within the 45 day window. In focus groups of parents most, but not all, recalled receiving information about the NET in the mail.[43] A few of the parents observed that the materials proved to be useful as a reference and as a means of verifying what the NET offered when subsequently the recruiter either called or visited. *However, the overwhelming majority of the respondents were of the opinion that mailing marketing information is not an effective approach*. Many admitted that they either threw the material away, dismissing it as junk mail, or that they kept it but did not read it. Some found the material hard to understand. Others said they were already overwhelmed by the amount of paperwork they have to fill out in order to access services for their children, and they were not motivated to read about a service which was not familiar to them.

5.1.2 Outreach by HSCSN

When a family does not respond within 45 days, HSCSN is permitted to locate these individuals to obtain a selection form and arrange for a health assessment if the family is interested in enrolling the child in the Net. HSCSN's outreach workers who conduct these initial visits are from the community and they are familiar with the neighborhoods in which most HSCSN enrollees live. If the family is not at home, the outreach worker leaves an announcement on the door handle. They also hand out a flyer which promotes the added benefits offered by the Demonstration (transportation, respite care, telephones, and care management).

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[43] At the time of the focus groups, families requiring translation services were not identifiable with the available data and the groups were not able to explore the barriers created by translation needs. In the most current listing of demonstration enrollees, 45 are noted as needing translation services.

Through the mailings and HSCSN efforts to locate and enroll families, the District has realized that a relatively large proportion of children can not be located, and others thought to be eligible have been found to be ineligible for demonstration services. While only seven percent of the mailings were returned as not deliverable by the post office, outreach efforts by HSCSN have failed to locate 1,610 children believed to be eligible (see Table 5.1).[44] HSCSN outreach workers go to some lengths to locate individuals through inquiries with neighbors. These part-time workers are also expected to develop relationships with different community organizations to establish contacts and develop a rapport. These organizations include police departments, Advisory Neighborhood Commissions (ANCs), tenants' associations, and service organizations that deal with social issues such as food, utility assistance, and housing. HSCSN has also worked to increase its general visibility through participation in community health fairs, T-shirts, and flyers in order to bring in portions of the eligible population they have been otherwise unable to locate.

When an outreach worker is able to find a family, the worker initially verifies the child's eligibility. If the child is not currently receiving SSI, the outreach worker will leave pamphlets about SSI and the Net, but otherwise not make a presentation about the program. As of November 1, 1997, the outreach effort has found 199 children to be ineligible (see Table 5.1).[45] Of those found to be ineligible, 56 had died, 124 had lost their SSI eligibility, three were found to be incarcerated, and one was dually eligible for Medicaid and Medicare and therefore not eligible for this Demonstration. The rest were too old to participate.

Among the children that could be located and were found to be eligible, only 443 have openly refused demonstration services and have never enrolled. Another 15 children were enrolled, but then disenrolled within two months because the family changed its mind about participating. These 458 children are termed active decliners (see Table 5.1). During the fall of 1997, HSCSN was given permission from the District to re-market the program to earlier decliners. As a result of this renewed marketing effort, HSCSN obtained an average of 125 selection forms during the months of August, September, and October compared to an average of 17 in the prior three months (see Table 5.2).

Lastly, a group of 332 *passive decliners* have been identified in the data (see Table 5.1). These families have indicated an interest in the program, but enrollment has never occurred and the files do not otherwise indicate that the child is ineligible. Among these decliners, 46 completed the assessment phase, but never enrolled.

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[44] Of these children, 377 have addresses outside the District of Columbia (Virginia and Maryland primarily) and it is not known to what extent the District and HSCSN have tried to determine the eligibility of these children; that is, whether the child is institutionalized or the family has moved out of the District.

[45] Twelve of these ineligible children were enrolled, but then immediately disenrolled suggesting that the Demonstration's initial effort to verify eligibility does not catch every case.

TABLE 5-1. Disposition of Non-Enrolled Cases as of November 1, 1997	
Can Not Locate	1,610
Ineligibles	194
Decliners	790
Active	458[a]
Passive	332

SOURCE: HSCSN's Marketing and Enrollment Files.

a. Fifteen children initially enrolled, but disenrolled within two months.

Grouping the active and passive decliners results in a total of 790 eligible children who have been contacted and whose families have not taken-up demonstration services. A focus group conducted with a group of active decliners discussed why some parents do not take-up this program. Predominately, these families have a general dislike for managed care. Either the family has directly had an unfavorable experience or has heard unfavorable stories from friends and family. One mother noted that the child's provider was not in the network and others believed the child's access to specialists would be hindered.

Whereas HSCSN has not been able to locate all children thought to be eligible, outreach workers have identified some of the eligible population missed by the District's retrospective review of records and their bulk mailing of enrollment packets. These workers have located 31 siblings of previously identified children and 196 other children.[46] While it is not known at this time why the District was unable to identify these particular children, given the absence of any other mechanisms to identify new SSI beneficiaries, it is likely that these children are disproportionately new SSI participants or new residents of the District of Columbia.

When an eligible child is found, the outreach worker will present the Demonstration program by discussing the benefits of managed care, the Net's mission, and benefit package. At the end of the presentation, which typically occurs in the child's home, a worker leaves a pamphlet describing the program, their phone number, and T-shirt. Commonly, the family indicates during this promotional visit interest in enrolling the child and the outreach worker immediately schedules a date for the health assessment.[47]

During focus groups with parents, several verified that their first contact with the NET was either through a telephone call or home visit by a NET outreach worker. Although most parents reported that they were surprised by the telephone calls and these visits, all thought that these marketing methods were more effective than a mailing. In addition, all of the participants who had received mailings as the first contact, reported that they subsequently received a telephone call or home visit, and it was these contacts that were most memorable and informative to them. None of the participants voiced any objection to the initial personal contacts. Many expressed the view that the appeal of having personal contact with NET representatives is that they were able to ask questions and to obtain a sense of the sincerity of the representatives,

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[46] More than half of these children (101) have been identified since August 1997.

[47] Outreach workers carry cellular phones which facilitate the immediate scheduling of these followup appointments.

which some took as an indicator of the probable attitudes of NET providers. Also, personal contact forced these parents, who are often occupied with child care, employment, and family, to focus on the offer and to assess it seriously, something which mailings did not have the power to do.

Some of the participants observed that the District and the NET should investigate other forms of marketing. Several mentioned radio, television and print advertisements. Others suggested bill boards or advertisements on public transportation. Also, these parents and their children are frequently at hospitals and other health facilities, and several suggested that health services providers, special education teachers, advocates for the disabled and those with special needs, and public service agency workers, particularly those who work for SSI, should be informed about the plan so that they can refer their clients to it.

Overall reactions to the Demonstration's marketing and recruitment efforts were mixed. As stated earlier, the mailing was not viewed as a success. Telephone calls and home visits met with more approval because they provided opportunities for questions and answers. Most of these parents asked the workers specific questions about the services their children would receive under the plan and whether they could retain the physicians and other providers that their children were currently using. Workers who were able to answer the questions in simple but comprehensive terms were highly rated by the parents. Parents were also impressed with workers who expressed a personal interest in them and who appeared knowledgeable about their children's health conditions.

However, across respondents there appears to be great variation in the quality of the information they received as part of the marketing effort. This variation would indicate that the telephone calls and personal contact were not as effective as they could have been. Whereas some participants received very comprehensive information about the benefits offered by the plan and how to access them, others appeared uninformed. During the focus group discussion the uninformed parents were observed to be taking notes about demonstration services. The benefit about which the uninformed respondents expressed the most surprise was respite services--a service they reported was acutely needed. The observed variation in knowledge concerning the NET appears largely attributable to variations in the presentations and explanations offered by the outreach workers and, in a few cases, by the care managers. Some participants spoke very enthusiastically about how knowledgeable the NET staff were. One mother stated:

> *"She fully explained everything to us."*

Others claimed that the outreach workers did not provide them with a thorough explanation of the benefit package. In some cases, they also complained that their care managers did not appear knowledgeable about the plan. In this regard, it is noteworthy that the majority of the participants who had enrolled their children in the NET, reported that they were not aware at the time when they decided to enroll their children that they had a choice. This lack of awareness is not surprising given that the District's Participant

Handbook that is sent in the initial mailing states "If you do not make a choice within forty-five (45) days of receiving this notice, your child will be assigned to the new managed care program." A few mentioned that they were confused by managed care but that the marketing effort left them with the impression that fee-for-service delivery was going to be eliminated so they opted to enroll in the NET. It is also interesting that only one participant in the focus group was aware of the NET's informational telephone hot line.

Besides the need to explain that enrollment is voluntary, the respondents had several recommendations about what information the NET outreach workers and care managers should be sure to offer parents of potential clients. Respondents thought that other parents would want to know about the eligibility requirements, the benefits, the transportation service, the care coordination services, and the low cost of prescriptions. They all stressed that written and oral communication should employ the simplest of terms and focus only on the essentials so as to ensure that parents would understand the plan and its benefit package.

5.2 Health Assessment

After a family has indicated an interest in enrolling the child in the Demonstration and has signed the selection form, contracted staff at HSCSN arrange a time when an in-depth health assessment can be conducted in the home. This assessment entails a lengthy interview which collects an inventory of information regarding the child's use of health, educational, and social services. The family is asked to report the child's diagnoses, the primary care provider if he or she has one, and functioning status, but this status is not tested or observed by the assessor.

As of November 1, 1997, HSCSN had recorded dates for 2,215 health assessments (see Table 5.2). In addition to these assessments, 38 children are enrolled in the program, but no assessment date is noted in their record so that it is likely that HSCSN has actually completed 2,253 assessments, averaging 102 assessments per month.[48] On average, 23 days lapse between the date HSCSN receives notification that the family has selected the Demonstration and the date of the health assessment. However, at least half of the children have their assessment within six days of HSCSN's receipt of the selection form. Once the assessment is complete, the child waits an average of another 37 days before enrolling.

Until September 1997, health assessments had been completed by contract workers hired by HSCSN on a temporary basis.[49] These workers typically had a background in health services, either as registered nurses or clinical social workers. HSCSN located these individuals through local universities and colleges. The use of

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[48] While the structure of the enrollment process has the family signing the selection form prior to the health assessment, children sometime have the health assessment prior to the family signing the selection form (296 cases). In the majority of these cases, the selection form is received within two weeks of the health assessment (256 cases).

[49] It is interesting to note that several of these individuals were eventually hired by HSCSN as care managers.

clinically trained staff was initially seen as critical because these assessments obtain information that is used by care managers to develop a comprehensive plan of treatment--the first necessary step in an effective care management system. During the fall of 1997, HSCSN altered this process by having the outreach workers take on the task of completing the health assessments. At this point it is not clear why HSCSN implemented this change.

During interviews with care managers, it was noted that the health assessment, while an effective tool, was not perfect. However, the problems noted are not unique to this Demonstration, but are found in many assessment processes. Families do not always know all the medical details of the child's condition and some are not always willing to provide sensitive information to someone they do not know and may not necessarily trust. As a result, care managers point out that sometimes important information is not discovered until after the child is enrolled and the care manager has established a relationship with the family.

During focus group discussions with parents there appeared to be considerable confusion as to if and when their children had received their comprehensive assessments. This confusion was surprising because the assessment is long, comprehensive, and reportedly takes about an hour to complete. Despite repeated efforts on the part of the focus group moderator to guide the respondents toward distinguishing between home visits made by outreach workers and the assessment process, only a third of the respondents could make the distinction.[50] These parents found the assessments to be helpful, thorough, and indicative of the NET's interest in and commitment to their children's health. Some parents were impressed by the emphasis on special needs in the assessment process.

Rather than finding the assessment time consuming, the majority of respondents found that the level of detail covered in the process as indicative of the NET's commitment to individualized care for its clients. According to the mother of one acutely ill child, the thoroughness of the assessment led to

> *"Actually narrowing down and assessing what exactly you need by the different questions that they ask. Determining what type of care you need or extra care."*

Most of the parents cited the caring attitude of their providers as one of the criteria by which they judged the quality of care. Accordingly, many participants were prompted to enroll their children because of the caring attitude of the outreach workers and care managers. These representatives of the NET appear to be absolutely crucial in "selling" the NET because they are often parents first point of contact with the plan and, therefore, exert considerable influence on the enrollment decision. Parents spoke of the compassionate treatment they received from outreach workers, who appeared to understand genuinely their stress and concern over their children's health. Others reported that the NET gave them a general feeling that they would receive help whenever they needed it. One participant stated

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[50] Two parents thought that the health assessment was done over the phone.

"If I need services, I'm pretty sure they'll help me."

Finally, learning that their child's primary care providers is a member of the NET and/or having the primary care provider recommend that they join the NET prompted a few parents to enroll their children.

5.3 Enrollment Experience

Enrollment in the Demonstration climbed steadily through its first year of operation. In fact, enrollment did not level out until the early summer of 1997. As of November 1, 1997, 1,901 children were enrolled in the Demonstration (see Table 5.2). On average, these enrollees have been in the Demonstration for a year. Half have been in at least 13 months. During the 22 months of operation, the Demonstration has served a total of 2,089 different children and has experienced a total of 26,286 member months.[51]

The average month sees 95 new enrollees. During the month of November 1997, the number of children enrolling jumped to 122 after an average of 22 new enrollees in the preceding four months. This jump can be directly related to HSCSN's effort to re-market the program to families who had earlier declined the program. In September when this marketing effort began, the number of health assessments jumped to 123 from an average of 25 in the preceding four months. The number of completed assessments dropped again in October to 50 and it is expected that the number of children enrolling in December will drop as well.[52]

The typical child spends two months in the enrollment process from the time the family notifies HSCSN that they are interested in enrolling the child, to the date of actual enrollment. Half wait 44 days or less between selection and the beginning of demonstration services.

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[51] Two children have disenrolled and subsequently re-enrolled. In one case the child temporarily lost SSI eligibility and in the other, the family voluntarily disenrolled the child.

[52] As of November 1, 1997, 28 children were in the process of enrolling and had completed the health assessment phase.

TABLE 5-2. Selection Forms, Health Assessments, and Enrollment

Month	Number of Selection Forms Returned		Number of Health Assessments Completed		Number Enrolling		Number Disenrolling		Total Enrollment	
	Monthly	Cumulative	Monthly	Cumulative	Monthly	Cumulative	Monthly	Cumulative	Monthly	Cumulative
December 95	21	21								
January 96	92	113	52	52						
February	346	459	224	276	8	8			8	8
March	187	646	176	452	149	157			157	165
April	212	858	134	586	190	347	5	5	342	507
May	198	1,056	158	744	125	472	3	8	464	971
June	128	1,184	126	870	145	617	3	11	606	1,577
July	163	1,347	178	1,048	135	752	2	13	739	2,316
August	120	1,467	139	1,187	123	875	1	14	861	3,177
September	30	1,497	76	1,263	214	1,089	15	29	1,060	4,237
October	240	1,737	150	1,413	69	1,158	11	40	1,118	5,355
November	18	1,755	43	1,456	104	1,262	6	46	1,216	6,571
December	9	1,764	106	1,562	96	1,358	7	53	1,305	7,876
January 97	34	1,798	67	1,629	83	1,441	9	62	1,379	9,255
February	85	1,883	54	1,683	63	1,504	6	68	1,436	10,691
March	199	2,082	120	1,803	108	1,612	4	72	1,540	12,231
April	129	2,211	140	1,943	30	1,642	7	79	1,563	13,794
May	31	2,242	30	1,973	145	1,787	10	89	1,698	15,492
June	9	2,251	15	1,988	95	1,882	20	109	1,773	17,265
July	11	2,262	19	2,007	23	1,905	15	124	1,781	19,046
August	112	2,374	34	2,041	11	1,916	14	138	1,778	20,824
September	160	2,534	123	2,164	20	1,936	27	165	1,771	22,595
October	152	2,686	50	2,214	33	1,969	14	179	1,790	24,385
November	53	2,739	1[a]	2,215	122	2,091[b]	11	190	1,901	26,286
Missing Date			38	2,253						

SOURCE: HSCSN's Marketing, Enrollment, and Health Assessment Files.

a. Incomplete Data
b. Two children disenrolled and subsequently re-enrolled so that the Demonstration has served 2,089 different children.

Not all children who enroll, stay in the Demonstration. Currently, 190 children have effectively disenrolled. At the time of the disenrollment, the average child had been in the Demonstration approximately eight months. Another 31 families have requested that the child be disenrolled and these requests will become effective in December 1997. Of these 221 children, 154 disenrolled due to loss of eligibility, either the child moved out of the District (92 cases), lost SSI benefits (29), were incarcerated (4), or aged out of the program (23). Another 14 children died. Only 53 children were voluntarily disenrolled by their families. Of these children, 20 were noted as giving no reason or no longer interested in the program. However, 28 stated that they did not like the provider network or the child's provider was not in the network and five indicated they did not like the authorization process.[53] Among all disenrollees, 32 were only enrolled for two months or less.[54] About half of these were voluntary disenrollments.

The small number of children who have been voluntarily disenrolled could be a strong signal that Demonstration participants are generally satisfied with the program. However, as noted earlier, many families do not appear to understand the voluntary nature of their enrollment in the program. While the initial focus group discussions revolved around the enrollment process and why parents choose to enroll or not enroll the child, parents enrolled in the program indicated that they were satisfied with the Net and its services, particularly in the areas of transportation and care management. In later work, the satisfaction of participating families will be more fully explored.

5.4 Characteristics of Enrollees and Disenrollees

A small amount of demographic and diagnostic information is available for Demonstration participants. Among those children currently enrolled in the program, the average age is 11 years, 64 percent are male, and 94 percent are African American (see Table 5.3). The enrollees are similar to a national sample in regards to gender, but the distribution of ages suggests that Demonstration participants are slightly older.[55] Less than one percent are infants compared to 1.5 percent nationally, while 14 percent are 18 or older compared to only six percent nationally. Differences are also evident in the race and ethnicity of Demonstration participants. Compared to the national sample of SSI children, Demonstration participants are more likely to be African American, 94 percent compared to 34 percent nationally. This difference is not surprising given the demographics of the District, but it is surprising that the Demonstration data identify so few white and Hispanic children. These children may be identified in the Unknown and Missing categories, as there may be confusion when Hispanic or mixed race

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[53] All but two of the 28 disenrollments due to provider network issues occurred after HSCSN servered the relationship with the District's public health clinics. This relationship ended because the clinics refused to present physician credentials to HSCSN. At this time, it is not clear what proportion, if any, of these cases are due to the public health clinics not being in HSCSN's network or to other network issues.

[54] In four cases, the child was enrolled and disenrolled on the same day due to the death of the child or the child's ineligibility for SSI benefits.

[55] The national data were obtained from *A Report to Congress of the National Commission on Childhood Disability*, 1995.

households are asked to classify the child. Information on race/ethnicity comes from the administrative eligibility files used by the Demonstration to locate eligible children and HSCSN updates this information during the assessment phase by determining racial and ethnicity characteristics of the child's household.

TABLE 5-3. Demographic Characteristics of Demonstration Enrollees, Disenrollees and a National Sample from June 1995

	Demonstration Enrollees as of November 1, 1997 (n = 1,901)		Disenrollees as of November 1, 1997 (n = 190)		National Sample June 1995 (n = 934,180)	
	Number	**Percent**	**Number**	**Percent**	**Number**	**Percent**
Age at Enrollment						
Less than 1 year	12	0.6	---	---	13,920	1.5
1 through 4	290	15.3	31	16.5	129,850	13.9
5 through 12	828	43.6	73	38.8	449,760	48.1
13 through 17	501	26.4	46	24.5	286,070	30.6
18+	270	14.2	38	20.0	54,580	5.8
Missing	---	---	2	1.1	---	---
Average Age	11 years	12 years	10 years			
Gender						
Female	684	36.0	79	41.6	341,530	36.6
Male	1,217	64.0	111	58.4	592,650	63.4
Race/Ethnicity						
White	4	0.2	1	0.5	340,730	36.5
African American	1,784	93.8	154	81.1	318,450	34.1
Hispanic	45	2.4	6	3.2	83,420	8.9
Unknown	66	3.5	23	12.1	27,910	3.0
Missing	2	0.1	6	3.2	163,670	17.5

SOURCES: HSCSN's Enrollment File and Social Security Administration, *Children Receiving SSI*, June 1995, ten-percent sample file as reported by the National Commission on Childhood Disability, 1995.

The disenrollees are very similar to Demonstration participants, but the small number of children in this group make these distributions unreliable. Those disenrolling appear to be slightly older (average age of 12 years and twenty percent are 18 years or older) reflective of the Demonstration's age limit, slightly more likely to be female (42 percent compared to 36 percent among enrollees), and less likely to be African American (81 percent compared to 94 percent among enrollees).

During the health assessment, families are asked to report the child's primary diagnosis and any secondary diagnoses. On average, enrollees have 1.4 reported diagnoses, but 102 have three or more. Table 5.4 shows that the most commonly reported primary diagnoses fall under the classification of mental disorders: mental retardation and psychotic and neurotic disorders and developmental impairments. Within this subgroup of children, 499, have a primary diagnosis of developmental delay or learning disability (see Table 5.5). Disorders of the nervous system or sense organs are also common (350 children or 18 percent of participants) as is mental retardation (243 children or 13 percent of participants).

When the distribution of primary diagnoses are compared to a national sample it is noted that nationally 56 percent of SSI children are classified under mental disorders, whereas 52 percent of Demonstration enrollees are so classified. Within the mental disorder group reported mental retardation is considerably less than what is reported nationally (13 percent compared to 36 percent). The dominance of relatively ill-defined developmental issues such as developmental delay and learning disability as a primary diagnosis is troubling. It is possible that these self-reported diagnoses could be proxies for other conditions such as mental retardation or an emotional disorder. When secondary diagnoses for this group of children are considered, 71 do not report any other diagnosis, while 10 percent report having asthma, four percent have a speech disorder, another four percent have Attention Deficit Disorder (ADD) or Attention Deficit and Hyperactivity Disorder (ADHD), and three percent have a seizure disorder.

TABLE 5-4. Diagnostic Grouping of Demonstration Enrollees, Disenrollees and a National Sample by Primary Diagnosis

	Demonstration Enrollees as of December 1, 1997 (n = 1,901)		**Disenrollees as of December 1, 1997 (n = 190)**		**National Sample June 1995 (n = 934,180)**	
	Number	**Percent**	**Number**	**Percent**	**Number**	**Percent**
Total with Diagnosis	1,718	90.4	113	59.5	783,500	83.9
Mental Disorders						
Mental Retardation	243	12.8	10	5.3	331,820	35.5
Psychotic and Neurotic Disorders and Development Impairments	751	39.5	50	26.3	189,310	20.3
Physical Disorders						
Infectious Diseases	37	1.9	2	1.1	2,860	0.3
Neoplasms	21	1.1	2	1.1	12,570	1.3
Endocrine	4	0.2	2	1.1	8,030	0.9
Diseases of the:	---	---	2	1.1	---	---
Blood and blood forming organs	52	2.7	3	1.6	---	---
Nervous system and sense organs	350	18.4	22	11.6	94,700	10.1
Circulatory system	8	0.4	1	0.5	5,580	0.6
Respiratory system	82	4.3	5	2.6	21,570	2.3
Digestive system	13	0.7	1	0.5	9,090	0.3
Musculoskeletal system	9	0.5	1	0.5	35,250	1.0
Congenital Anomalies	98	5.2	10	5.3	35,250	3.8
Conditions Originating in the Perinatal Period	28	1.5	2	1.1	---	---
Injury and Poisoning	20	1.1	2	1.1	4,910	0.5
Other	2	0.1	---	---	65,240	7.0

SOURCES: HSCSN's Enrollment and Assessment Files and Social Security Administration, *Children Receiving SSI*, June 1995, ten-percent sample file as reported by the National Commission on Childhood Disability, 1995.

Considering physical disorders is more difficult due to the wide range of conditions, many which are extremely rare (see Table 5.5). When primary and secondary conditions are considered together, those with physical disorders are dominated by children with cerebral palsy (203 children). Other common conditions are HIV/AIDS, Sickle Cell disease or trait, seizure disorder, asthma (primarily a secondary diagnosis), Down's Syndrome, and hydrocephalus.

TABLE 5-5. Self Reported Diagnoses of Enrollees (n = 1,901)

Classification of Diagnoses	Count of Primary Diagnoses	Count of Primary and Secondary Diagnoses
Mental Retardation	**243**	290
Mental Disorders	**751**	
ADD or ADHD	66	112
Autism	44	50
Behavior Disorder	---	2
Bipolar Disorder (BPD)	1	2
Depression	2	3
Developmental Delay	172	207
Dysthymic Disorder	1	5
Emotional Disorder	63	91
Learning Disability or Dyslexia	327	398
Mental Disorders	12	21
Pervasive Development Disorder	1	1
Schizophrenia	7	8
Speech or Language Disorder	55	119
Infectious Diseases	**37**	
Candidiasis	1	2
HIV/AIDS	36	39
Lyme Disease	---	1
Neoplasms	**21**	
Brain Tumor	1	2
Bronchopharyngeal Papilloma	1	2
Leukemia	6	6
Malignant Neoplastic Stomach	1	1
Malignant Solid Tumors	3	3
Neuroblastoma	1	1
Neurofibramatosis	4	4
Rhabdomyosarcoma	1	1
Osteosarcoma	---	1
Wilms' Tumor or neoplasm	3	3
Endocrine	**4**	
Congenital Adrenal Hyperplasia	---	2
Cystic Fibrosis	1	1
Diabetes	2	4
Obesity	---	3
Parathyroid Disorders	1	1
Thyroid Disorders	---	5
Diseases of the Blood	**52**	
Hemophilia	5	6
Hemolytic Anemia	---	1
Sickle Cell Disease or Trait	47	55

TABLE 5-5 (*continued*)		
Classification of Diagnoses	**Count of Primary Diagnoses**	**Count of Primary and Secondary Diagnoses**
Diseases of the Nervous System	**350**	
Blind/Glaucoma/Vision Impairment	23	39
Cerebral Palsy	187	203
Deafness/Hearing Impairment	48	84
Fetal Alcohol Syndrome	14	16
Hemiparesis	1	2
Hemiplegia	1	1
Leukodystrophy	3	3
Migraine	---	2
Muscular Dystrophy	7	7
Paralysis	6	6
Retinitis Pigmentosa	3	3
Retinofibroplasia	1	1
Rett's Syndrome	1	1
Seizure Disorder or Epilepsy	55	141
Diseases of the Circulatory System	**8**	
Cardiovascular Disease	1	4
Circulatory System Malfunction	2	4
Congestive Heart Failure	2	2
Hypertension	1	3
Spinal Muscular Atrophy	1	1
Supraventricular Tachycarbia	1	1
Diseases of the Respiratory System	**82**	
Asthma	57	245
Bronchopulmonary Dysplasia	15	21
Chronic Bronchitis	---	1
Lung Disease	3	7
Pulmonary Disorder/Insufficiency	5	5
Respiratory distress Syndrome	2	3
S/P Tracheostromy	---	2
Diseases of the Digestive System	**13**	
Esophageal Obstruction	2	2
Inflammatory Bowel	---	1
Intestinal Malabsorption	2	2
Liver Disease	2	2
Nephrotic Syndrome	2	2
Renal Disease	1	3
Short Bowel Syndrome	4	4
Diseases of the Musculoskeletal System	**9**	
Aseptic Necrosis	---	1
Blount's Disease	3	4
Disarticulation of the hip	1	1
Juvenile Rheumatoid Arthritis	1	1
Scoliosis	3	7
Systemic Lupus Erythematosus	1	1

TABLE 5-5 (*continued*)		
Classification of Diagnoses	**Count of Primary Diagnoses**	**Count of Primary and Secondary Diagnoses**
Congenital Anomalies	**98**	
Amniotic Band Syndrome	2	2
Apnea	1	3
Bilary Atresia	---	2
Cleft Palate	2	4
Congenital Birth Defect	1	2
Congenital Mitral Stenosis	1	1
Craniosynostosis	1	1
Down's Syndrome	40	42
Dwarfism	1	1
Fragile X Syndrome	1	1
Hirschsprung's Disease	---	1
Hydrocephalus	27	37
Hypotonia	---	1
Klinefelter's Syndrome	---	1
Klippel Trenaunay Weber	1	1
Marfan's Syndrome	3	3
Noonan's Syndrome	1	1
Osteogenesis Imperfecta	1	1
Pulmonary Artery Branch Stenosis	1	1
Russell Silver Syndrome	1	1
Spina Bifida	11	13
Tetralogy of Fallot	1	1
Trisomy 21	---	1
Vater Syndrome	1	1
Conditions Originating in the Perinatal Period	**28**	
Low Birth Weight	5	9
Premature Birth	23	24
Injury and Poisoning	**20**	
Burn	1	1
Injury Spinal Cord or Head	15	18
Lead Poisoning	4	5
Other	**2**	
Amputee, bilateral	1	1
Eczema	1	11
Immune Deficiency	---	1
Rickets	---	1

SOURCE: HSCSN's a Enrollment and Health Assessment files.

5.5 Considerations for Other States and Interested Entities

Staff at HSCSN and the District view this three-step enrollment process as problematic, but they are managing the process and most would admit that the Demonstration has achieved a high rate of enrollment. The first, and probably the most significant problem, has been locating the eligible population. Because the targeted population has unstable housing and is highly mobile, this problem would have appeared regardless of the enrollment process and is one that is frequently faced by demonstrations involving low-income households. This problem has been compounded by District-level record keeping problems which are also not unique to the District. In the short-term, HSCSN continues to focus its outreach and marketing efforts on locating the children currently believed to be in the SSI program and few plans have been put into place to systematically locate and market the program to children newly eligible for SSI benefits.

Even if the Demonstration had mandatory enrollment, or if HSCSN did not have to wait 45 days prior to directly marketing the program to eligible children, HSCSN would still have had to expend considerable resources locating these children and ascertaining their eligibility. As the Demonstration goes forward, these problems are likely to persist as low-income households will continue to have unstable housing. It is likely that the outreach and care management staff will expend considerable resources tracking enrollees as they move within the District and across state boundaries. During interviews with care managers, several indicated that it is common for them to ask the outreach department to find a family and assist in the follow-up that is part of HSCSN's care management process.

While the requirement that the District and HSCSN must first find the eligible population prior to enrollment has necessitated a larger outreach and marketing effort than what was initially conceived, from the families' perspective this has been a favorable and appreciated aspect of the Demonstration. As noted above, families indicate that the personal attention of a home visit and an opportunity to ask questions is their first memorable impression of the Demonstration and the type of service they might expect. As long as outreach staff appear to be knowledgeable, treat prospective enrollees with respect, and demonstrate concern for the needs of the child and family, families are likely to continue to appreciate this personal touch. Had an enrollment broker been used, it is unlikely that families would have had such a favorable first impression. Of course, the concern is whether or not the outreach staff, who are employees of the plan operating the Demonstration, provide misleading information or coerce families. Parents in the focus groups did not suggest that this has been happening and disenrollment associated with dissatisfaction is not evident in the data. However, many do not understand the program is voluntary and are unaware of informational hotlines.

The second step in the enrollment process, the health assessment, is also perceived as problematic. The plan views this step as a business function for which they are not paid. When the Demonstration was initially conceived, Demonstration staff viewed the health assessment as the first service the child would receive after entry into the Demonstration. The assessment is the starting point for care management and necessary for the development of a comprehensive plan of treatment. As such, HSCSN had initially anticipated that the child's capitated payment would begin just prior to the health assessment, rather than after the completion of the assessment. However, if costs associated with the health assessment can not be covered through the capitated rate, then the sharing of any losses and profits with the District through the risk corridors should compensate the health plan.[56]

In general, the health assessment phase has received mixed reviews. The families do not mind this step, even though the assessment is long. It provides another opportunity to ask questions about the benefit package and become comfortable with the staff at the Net. From HSCSN's point of view, while the assessment gathers together information vital to the care management process, they realize that it is imperfect, but these imperfections are true of most initial assessments. Families do not always know about all of the child's medical issues or have the language to describe them. Some will be unwilling to reveal information until later on when they have developed a trusting relationship with the care manager. As a result the health assessment phase is only the beginning of the needs determination process.

Until recently, the staff conducting the health assessments had some type of clinical background either as an ancillary provider such as a nurse or therapist or as a clinical social worker. The benefit of using staff with this type of background is that the health assessment is likely to be more accurate than otherwise because these individuals have experience in taking health histories and doing similar types of assessments. From the families' perspective, these individuals are likely to appear to be very knowledgeable about the child's issues and present a favorable impression. Currently, HSCSN is using their outreach workers to do these assessments. These individuals are not likely to have clinical training or prior experience in doing health histories or assessments. This change also further blurs the line between marketing and the assessment process.[57] It is too soon to tell whether the information obtained is of poorer quality or that the number of families electing not to enroll after the assessment has increased, direct signals that clinically trained assessors have been a critical element in the enrollment process.

In addition to these issues, the Demonstration has had some information management issues associated with the enrollment process. During the 22 month design and waiver application stage, the board for the Hospital for Sick Children provided $5.4 million in funding for this Demonstration, $2 million of which was spent on designing the management information system. While the issues confronted to-date have not hindered enrollment in any way, they are issues that others planning similar efforts will want to consider. Any information system faces data quality issues. In this Demonstration data quality issues center on several key pieces of information. First are dates: dates that track the receipt of selection forms, health assessments, and enrollment. In some cases date information suggests that enrollment occurred prior to the receipt of the form or the assessment and not all enrollees have a recorded assessment date. For research purposes, it is not always clear whether the dates are

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[56] After the conclusion of the first full year of operations, HSCSN was prepared to share profits and make a payment to the District.

[57] The distinction between marketing and assessment visits had been very fine. Health assessment workers, while contracted, were employees of HSCSN, and families had difficulty distinguishing between the initial marketing visit and the health assessment visit.

correct and the enrollment process was not followed, or dates are incorrect. In some cases, old dates are overwritten and updated so that not all historical information is maintained. This will happen if a family submits multiple selection forms, such as when a second form is submitted during HSCSN's efforts to re-market the program to earlier decliners, or upon a reversal of its initial decision to decline the Demonstration. Some of these problems reflect HSCSN's initial perception that the enrollment process would be a one-step mandatory system.

Second, and probably most important, are Medicaid ID numbers. HSCSN's management information system, which is composed of a series of relational databases, is keyed on the child's Medicaid ID number. This system requires that each ID number be unique. While this facilitates the identification of each child, children may change Medicaid ID numbers. As a result, some children appear multiple times in the files which makes the tracking of these children across files and time problematic.

5.6 Future Areas of Investigation

One of the critical issues not discussed in this report is the extent of selection bias in this Demonstration. In order to study this issue, data on the health status and the costs of care for those not enrolling need to be obtained. While enrollment into the Demonstration has been successful (the 1,901 children enrolled reflect 71 percent of the population that has been located and determined to be eligible), little is known about those not enrolling. In a population with chronic and disabling conditions, health care is extremely variable and small groups of children, such as those in institutions, can be extremely costly. The small group not enrolling may contain some of the most costly children in the public health system. The same is also true of those eligible children that have not been located.

Earlier, self-reported diagnoses of enrollees and dis-enrollees were compared against the diagnostic group to which a national sample of SSI children were assigned. Other than some differences within the group of mental disorders, there was nothing to suggest that the Demonstration has been experiencing any type of selection bias. However, this type of comparison is extremely weak and should not be considered conclusive. The diagnoses of enrollees and dis-enrollees are those reported by the families and have not been confirmed by clinical evidence. For those in the national sample, the diagnoses are those used by SSI determination staff and medical evidence is only gathered to the extent necessary to determine eligibility. The use of diagnoses to examine selection issues is problematic, impairments frequently occur in combinations and diagnoses provide little insight into the nature and extent of the impairments, the child's level of functioning, utilization of health care services or assistive technology.

5.7 Future Prospects: What Could Make a Difference?

Because the Demonstration has not ended, the results presented here may or may not carry through as the Demonstration proceeds. Currently, it is anticipated that enrollment patterns may change if there are critical changes in either the enrollment process, or there are fundamental changes in the general environment in which this Demonstration operates, or the benefit package and how components of that package are accessed are changed.

Any change to any component of the enrollment process could have impacts on the number of children who reach the health assessment phase, the number who actually enroll, and the number who stay enrolled. Recently HSCSN has changed the staffing for the health assessment and because parents in focus groups have indicated that their initial experience with staff is critical to their feelings about the Demonstration, this change could influence the number enrolling after the health assessment stage and/or the number dis-enrolling soon after entering the program. But this is a relatively small and subtle change. More significant changes would involve either a major adjustment in the enrollment process, such as the elimination of a step, or the addition of another step, or an environmental change such as the introduction of a competing plan and/or mandatory enrollment.

Environmental changes would be more difficult to track, such as the District's stalled attempt to enroll all welfare recipients into one of several managed care plans, the recent changes in SSI eligibility rules, and changes to the welfare system. The District of Columbia would like to have all Medicaid beneficiaries in managed care as a way to control costs. If the court system allows the District to proceed with its attempt to mandate enrollment into one of several managed care plans, then general attitudes toward managed care within the low-income population may change. During focus group discussions, parents who had actively declined demonstration services cited a general dislike for managed care as the reason for not enrolling the child. Depending on what other managed care organizations do with their benefit packages and access to components of that package, either general attitudes toward managed care will improve as more families are enrolled in managed care plans and have reasonably good experiences, or worsen if they do not.

If attitudes worsen, HSCSN will face a more skeptical population. It will have to take steps to emphasize that for a child with special needs, managed care presents the opportunity of providing a more flexible health care system for these children. It can eliminate some of the rigidities of the Medicaid fee-for-service system, such as a time consuming authorization process for durable medical equipment, and it can offer enhanced benefits such as transportation, respite services, and care management. Toward this end, HSCSN has been savvy in its use of outreach workers who represent the Net in the neighborhoods. These individuals are neighbors of the eligible children, and frequently they are family members of enrollees.

It has also been anticipated that recent tightening of Federal SSI eligibility guidelines for children would affect enrollment in this Demonstration. Since May 1997, disenrollments have been averaging about 16 children each month, whereas prior to this period monthly disenrollment averaged about six children. However, the majority of children are disenrolled because they move out of the District. As noted previously, only 29 have been disenrolled due to the loss of SSI benefits. Of these, the files only indicate that six children lost benefits due to the new regulations. Staff at HSCSN have indicated that care managers and staff in the outreach and marketing department have provided families with some assistance to help them maintain benefits. Also, staff have begun to work with providers to improve their understanding of the eligibility determination process and to improve their ability to identify children who could potentially qualify for these benefits. If, because of these efforts, families with children in the Demonstration are more likely to comply with the redetermination process and appeal negative decisions, then it may be some time before the changes to the eligibility standards are fully realized in this Demonstration.

The last environmental change that could have impacts on this Demonstration are the changes to the welfare system that resulted from the Welfare Reform Act of 1996. Because the SSI program is part of the Federal welfare system, changes to one component of this system are likely to influence other parts. As welfare requirements become more restrictive and long-term recipients exit, it is possible that more families will look to the SSI program as a way of maintaining Medicaid benefits for at least some family members. If so, the number of SSI applications can be expected to increase, but whether these new applications will result in new SSI beneficiaries is unknown at this time. The success rate of new applications may be relatively greater in the District if HSCSN's workshops with providers are able to effectively improve provider abilities to detect qualified children and prepare appropriate documentation for the determination process.

The last consideration is whether HSCSN institutes any changes to their benefit package and access to particular benefits. The main finding of the first focus group study is that the decision to enroll was most closely related to perceptions about the accessibility and quality of services that the NET promised to provide.[58] Gaining timely access to services emerged as a major concern of most parents. Therefore, the NET's transportation benefit was the principal deciding factor for many parents, who welcomed being relieved of the constant worry over trying to find transportation to and from appointments. One parent observed that with the NET

> *"Parents don't have to worry about how to get your child to services if you don't have transportation. The NET will provide transportation immediately."*

Another reason parents cited for enrolling their children was the NET's promise to assist parents to access services promptly by coordinating care, making appointments, and other aspects of care management. Some parents had specific needs that they

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[58] Subsequent focus group studies will explore in greater detail parents' reactions to the benefit package and service delivery, including the care management process.

anticipated the NET could address. For example, one mother was excited by the prospect that the NET care managers could help her obtain appropriate special education services. Some parents who had been frustrated by the complicated paperwork, long waiting times, and difficulties in obtaining specialized equipment or services, such as braces or psychiatric assessment, that characterized the services they received prior to joining NET, were encouraged to enroll because of the NET membership card offered them relatively easy access to these services.

Thus, if HSCSN changes these aspects of the benefit package in a way that diminishes this satisfaction, disenrollment rates are likely to increase. The Demonstration has not been managing care in a traditional sense through restrictive prior authorization processes, physician gatekeepers, and penalty co-payments for inappropriate use of health services such as emergency rooms. If HSCSN incorporates more traditional management techniques into its care management system, levels of dissatisfaction may rise.

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EVALUATION OF THE DISTRICT OF COLUMBIA'S 1115 WAIVER FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Reports Available

Evaluation of the District of Columbia's Demonstration Program, "Managed Care System for Disabled and Special Needs Children": Year One Report

Executive Summary	http://aspe.hhs.gov/daltcp/reports/dc-yr1es.htm
HTML	http://aspe.hhs.gov/daltcp/reports/dc-yr1.htm
PDF	http://aspe.hhs.gov/daltcp/reports/dc-yr1.pdf

Evaluation of the District of Columbia's Demonstration Program, "Managed Care System for Disabled and Special Needs Children": Year Two Report

Executive Summary	http://aspe.hhs.gov/daltcp/reports/dc-yr2es.htm
HTML	http://aspe.hhs.gov/daltcp/reports/dc-yr2.htm
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Evaluation of the District of Columbia's Demonstration Program, "Managed Care System for Special Needs Children": Final Report

Executive Summary	http://aspe.hhs.gov/daltcp/reports/dc-fres.htm
Report Summary	http://aspe.hhs.gov/daltcp/reports/dc-frs.htm
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