Achieving Service Integration for Children with Special Health Care Needs: An Assessment of Alternative Medicaid Managed Care Models

Volume II: Case Studies

Prepared by:

Ian Hill, Beth Zimmerman, Renee Schwalberg, and Wilma Tilson
Health Systems Research, Inc.
Washington, DC

Prepared for:

The Division of Children with Special Health Care Needs
Maternal and Child Health Bureau
Health Resources and Services Administration
Rockville, MD
Cooperative Agreement No.: 93-110-C

July 1999
Volume II

Table of Contents

Case Study: Arizona ..................................................... 1
  I. Background and Introduction ..................................... 1
  II. The Models .................................................................. 6
      III. Lessons Learned Regarding Service Integration .......... 26

Case Study: District of Columbia ........................................... 32
  I. Background and Introduction ..................................... 32
  II. The Model .................................................................. 34
      III. Lessons Learned Regarding Service Integration .......... 46
      IV. Conclusion ............................................................ 54

Case Study: Florida .......................................................... 55
  I. Background and Introduction ..................................... 55
  II. The Model .................................................................. 59
      III. Directions for the Future and Lessons Learned Regarding Service Integration .......... 73
      IV. Conclusion ............................................................ 81

Case Study: Maryland ........................................................ 82
  I. Background and Introduction ..................................... 82
  II. The Model .................................................................. 84
      III. Lessons Learned Regarding Service Integration .......... 102

Case Study: Michigan ........................................................ 112
  I. Background and Introduction ..................................... 112
  II. The Model .................................................................. 113
      III. Directions for the Future and Lessons Learned Regarding Service Integration .......... 124
Case Study: Minnesota ................................................. 133
I. Background and Introduction ............................. 133
II. The Models ........................................... 134
III. Directions for the Future and Lessons Learned
    Regarding Service Integration ......................... 146

Case Study: Oregon .................................................... 151
I. Background and Introduction ............................. 151
II. The Managed Care Model ................................ 153
III. Lessons Learned Regarding Service Integration ............... 169

Case Study: Tennessee .................................................. 177
I. Background and Introduction ............................. 177
II. The Model ........................................... 178
III. Lessons Learned Regarding Service Integration ............... 190
Case Study: Arizona

I. Background and Introduction

The State of Arizona has implemented a very complex model for delivering and financing services for children with special health care needs (CSHCN) under managed care. To fully grasp the model, one must understand the workings of four separate, but interrelated systems that each serve either a subset of the population, or a subset of the population’s service needs.

The first, and principal, component of the managed care system is the Arizona Health Care Cost Containment System (AHCCCS), the label given to Arizona’s Medicaid program. AHCCCS began on October 1, 1982 under a Section 1115(a) research and demonstration waiver approved by the federal Health Care Financing Administration (HCFA). Prior to 1982, Arizona was the only state that did not have a Medicaid program. It was through AHCCCS that Arizona implemented the nation’s first statewide Medicaid managed care system based on capitated arrangements with private health plans. AHCCCS was envisioned as a partnership that would use private and public managed health care plans to mainstream Medicaid recipients into private physicians’ offices, thereby improving quality of care, controlling costs, and decreasing the use of emergency rooms as a source for primary care. The move to Medicaid managed care stemmed from state policymakers’ concerns over the growing cost of indigent health care and the burden it was causing the counties; prior to AHCCCS, health care for the indigent was provided and fully funded by Arizona counties, which relied primarily on county hospitals to deliver services.

In 1988, a second, separate Medicaid managed care system was introduced in Arizona. Called the Arizona Long Term Care System, or ALTCS, this program was originally designed to serve adults and children with developmental disabilities (DD) who were at risk of institutionalization; in 1989, elderly and physically disabled (EPD) populations were also made eligible for ALTCS. Persons who meet the fairly restrictive ALTCS eligibility criteria receive all their care through the ALTCS system, which is overseen by AHCCCS but managed on a day-to-day basis by...
another state agency—the Department of Economic Security’s Division of Developmental Disabilities (DDD). Like AHCCCS, ALTCS is a fully-capitated system; DDD receives monthly per capita payments from AHCCCS in return for managing all of the care needed by ALTCS enrollees.

Beginning in 1990, a third managed care component was added to Arizona’s Medicaid program. That year, the state began phasing in coverage of behavioral health services through managed care arrangements. Today, mental health and substance abuse services for adult and child AHCCCS enrollees are covered on a capitated basis through a contract with the Department of Health Services’ Division of Behavioral Health Services which, in turn, subcontracts with five Regional Behavioral Health Authorities (RBHAs). These services are “carved out” of the responsibility of AHCCCS plans and delivered and financed through the separate RBHA system.

Finally, the fourth system of care that is pivotal in meeting the needs of CSHCN in Arizona is the Children’s Rehabilitative Services (CRS) Program, administered by the Department of Health Services’ Office of Children with Special Health Care Needs (OCSHCN), the state Title V grantee. Since 1929, CRS (and its predecessor Crippled Children’s Services) has represented an organized system for providing and financing specialty medical care for children possessing one or more of the conditions identified by CRS as eligible for coverage. CRS has always worked in partnership with pediatricians in the private sector to support its clinic operations; CRS-employed nurses, social workers, rehabilitative therapists, and others work side-by-side with private physicians who receive negotiated rates to serve CRS-eligible children. Today, CRS conducts 22 distinct specialty care clinics primarily at four clinic locations strategically distributed across the state; these clinics treat a wide range of surgical, medical, dental, and genetic needs, and are characterized by their multidisciplinary team approach to service delivery. It was because of CRS’s long history of providing high quality care to CSHCN that it was included, from the outset, as a component of the AHCCCS system designed to meet the specialty care needs of Medicaid children with CRS-eligible conditions. CRS’ specific arrangement with AHCCCS is as follows: CRS receives a set annual budget from the Department of Health Services to serve all children in the state with CRS-eligible conditions.
All services required by AHCCCS-eligible children to treat their CRS-eligible conditions are “carved out” of the responsibility of AHCCCS managed care plan, and these services are rendered and financed by CRS, which receives federal Medicaid match for its expenditures on behalf of AHCCCS enrollees. Of the 16,000 medically-complex children served by CRS each year, 70 percent are also in AHCCCS (NACH, 1997).

To summarize, all four of these systems come into play in serving Arizona’s CSHCN under managed care. Specifically, Medicaid-eligible CSHCN can receive their care through either of two fully-capitated managed care systems, as described below.

- The general Medicaid population, including those on SSI, are enrolled into AHCCCS and receive their primary and acute care from “mainstream” managed care plans under contract with the state. However, all specialty medical services needed by children to treat CRS-eligible conditions are “carved out” of the responsibility of AHCCCS plans and must be provided through CRS. Similarly, all behavioral health services are “carved out” as well, and must be rendered and financed through the RBHA system.

- For children with developmental and physical disabilities that meet specific severity criteria, enrollment into managed care occurs through the ALTCS system. These children have *all* of their care organized by the state DDD agency, which receives a single capitation rate to deliver and arrange service delivery on behalf of ALTCS enrollees.

Together, these two models offer distinctly contrasting approaches to serving CSHCN under managed care. Arizona was selected for inclusion in this study for this reason. Within a single state, we were permitted to observe one model that enrolls CSHCN into “mainstream” managed care plans, yet relies on significant carve-outs for selected clusters of services; as well as a unique capitated model designed and organized to meet the full range of needs of persons with severe disabilities. The remainder of this report will discuss the strengths and weaknesses of both of these models.
A. Structure and Approach to State Site Visits

The information presented in this case study was drawn from interviews conducted by researchers from the National Policy Center for Children with Special Health Care Needs with key informants representing a wide range of state and local providers, program administrators and parents involved in systems of care for CSHCN. In the summer of 1998, extensive, structured telephone interviews were held with AHCCCS and CRS officials to develop a general understanding of the Medicaid managed care models in Arizona and to determine how services are delivered to children with special health care needs. These interviews also permitted the researchers to discuss and identify other key system stakeholders to be interviewed during a follow-up site visit that explored more deeply the structure and operations of the AHCCCS and ALTCS systems.

In December 1998, researchers conducted a three-day site visit to Phoenix, Arizona. Both individual and group interviews were held during this visit with officials from the AHCCCS, the Department of Health Services, the Division of Developmental Disabilities, the Department of Education, the Division of Behavioral Health Services; parents of children with special health care needs; the director and various staff from the CRS regional clinic at St. Joseph’s Hospital; ALTCS medical eligibility staff; the medical director and various staff from two AHCCCS plans—Arizona Physicians Individual Practice Association (APIPA) and Mercy Care; a representative from Value Options, one of the Regional Behavioral Health Authorities associated with AHCCCS’s behavioral health “carve out;” and a community-based primary care provider who serves a large number of CSHCN. (A list of key informants can be found in Appendix A.) Each of the interviews was guided by one of several structured protocols targeted to the particular orientation of the interviewee.
B. Organization of Report

The remainder of this report is divided into two sections. Section II discusses in detail the AHCCCS and ALTCS models. Section III provides a synopsis of the lessons that were learned from the site visit regarding the development and operation of Arizona’s two Medicaid managed care systems that serve CSHCN, and explores the extent to which the alternative models support an integrated approach to service delivery for CSHCN and their families.

II. The Models

In Arizona, there exist two Medicaid managed care models that serve different populations of CSHCN; the AHCCCS model, which delivers primary and acute services through mainstream managed care organizations, with specialty and behavioral services “carved out” to separate systems, and the ALTCS model which centralizes responsibility for all service delivery within a single system that receives capitated payments to serve a subset of the CSHCN population. Each model is described below, in turn, with discussion focused on processes for identifying and enrolling CSHCN into managed care; systems for the delivery of primary and specialty medical care and behavioral health services; the provision of care coordination by various programs; and linkages between AHCCCS and ALTCS and other systems that serve CSHCN.

A. Overview of AHCCCS

The State of Arizona describes AHCCCS as a fully-capitated health care cost containment system designed to administer innovative managed care programs effectively and efficiently, and to continually improve the accessibility and delivery of quality health care to eligible members through integrated health care systems (AHCCCS, 1997). The acute care program is delivered through 12 contracted health plans based on a prepaid capitated approach. Health plans negotiate capitation rates with AHCCCS, but rates are set within an actuarial range developed by the state based on 10 rate classifications, which include two groups of SSI-eligible—those with Medicaid and those without; thus, specific rates are not set for SSI-eligible children and the
rates are not risk-adjusted. Each health plan contracts with a network of providers to administer primary care services to recipients. Among these providers are 11 Federally Qualified Health Centers which help to expand access to health care services in medically underserved areas. There are over 430,000 Arizonians currently enrolled in AHCCCS, including about 10,000 SSI disabled children (NACH, 1997).

As mentioned above, in addition to acute health care services, AHCCCS enrollees receive behavioral health and specialty care services through two “carve-out” arrangements. Behavioral health services, including care to address mental health and substance abuse needs, are supported through a contract with the Department of Health Services (DHS) which is paid a per capita rate by the AHCCCS agency for the delivery of behavioral health services for all Medicaid eligible persons under the age of 18, all severely mentally ill (SMI) persons who are 18 years or older, and non-SMI adults age 21 years or older.\(^1\) DHS, in turn, subcontracts with five Regional Behavioral Health Authorities (RBHA) located throughout the state at sub-capitated rates. These RBHAs contract with networks of providers at capitated or fee-for-service rates for the direct delivery of behavioral health services.

Medicaid-eligible CSHCN with CRS-eligible conditions\(^2\) must receive specialty care related to their condition from one of four regional CRS multi-specialty clinics. These clinics are located in Phoenix, Tuscon, Flagstaff, and Yuma. The four CRS clinics each receive a negotiated annual lump-sum payment from the state to cover the costs of service delivery; these amounts are based primarily on the number of children served by each clinic, but also on the types of services each provides.

\(^1\)Behavioral health services for non-SMI persons who are 18, 19, and 20 years of age are provided through the AHCCCS health plans.

\(^2\)CRS general eligibility requirements are that the individual must be an Arizona resident under age 21 and have a physical disability, chronic illness, or a condition that is potentially disabling. CRS eligibility requirements will be further discussed in later sections.
The succeeding sections present more detailed information on various aspects of the AHCCCS system, focusing on the extent to which the system’s design supports effective service integration for CSHCN.

1. Enrollment, Identification, and Eligibility

Like all children in the state, CSHCN who apply for and meet the income eligibility guidelines for Medicaid are mandatorily enrolled into AHCCCS plans. There is an open enrollment period at the start of each contract year. At that time all Medicaid-eligible persons are allowed to select a plan from at least two that are available in their county, as well as a primary care physician within that plan’s network of providers. If the member does not select a health plan, AHCCCS will automatically assign the recipient to an available health plan in the zip code where the member resides. There is no enrollment broker associated with AHCCCS to assist persons with the selection process. Eligible applicants are simply given information on the available plans in their area and an application to enroll in a plan. Children who are eligible for AHCCCS through SSI, as well as those with CRS conditions, are treated like all others in this process; no subsystem exists for identifying their special needs or guiding them toward plans with particular capacity, experience, or expertise in meeting those needs. Many key informants interviewed for this study expressed concern that AHCCCS plans commonly do not know which of their child enrollees have special health care needs.

The CRS program maintains its own eligibility and enrollment process. To qualify medically for CRS, each child is evaluated in a CRS pediatric screening or specialty clinic by a member of the CRS medical staff. Physician and/or ancillary provider staff determine if the child has a handicapping or potentially handicapping condition that is eligible for treatment in a CRS clinic. The medical conditions generally accepted for care include but are not limited to:

- Deformities present at birth or acquired, such as club feet, scoliosis, dislocated hip, cleft palate, mal-united fractures, and spina bifida;

---

3Once a Medicaid member chooses or is assigned a health plan the member is “locked-in” to the health plan until the next open enrollment period. AHCCCS will allow an exception to the lock-in period primarily to provide for medical or family continuity of care (AHCCCS, 1997).
- Various muscle and nerve disorders;
- Some conditions of epilepsy;
- Heart conditions due to congenital deformities and those resulting from rheumatic fever;
- Cerebral palsy where mental and physical status is such that they are amenable to treatment;
- Certain eye and ear conditions;
- Cystic fibrosis;
- Burn scars that are causing functional limitations;
- PKU and other related metabolic disorders;
- Sickle cell anemia; and
- Neurofibromatosis (ADHS, 1998).

For those children found eligible for CRS who are also Medicaid eligible, CRS will notify the appropriate AHCCCS plan of the child’s qualifying condition so that future referrals to CRS for related treatment can occur.

It is important to note, however, that there are large numbers of CSHCN who do not fit within the CRS program’s condition-specific eligibility list, including children with hemophilia, diabetes, asthma, and those requiring transplants. Once again, AHCCCS has not implemented a systematic process for identifying CSHCN and, therefore, many such children may go unnoticed and without coordinated plans of care to meet their needs.

2. Primary Care

CSHCN have the same needs as other children for preventive health care and episodic care for acute illness in addition to their need for more specialized services. Ensuring adequate primary care services to manage these needs is critical to creating a comprehensive coordinated system
of care for special needs children. Arizona recognizes the importance of regular primary and preventive care for all children as demonstrated in its efforts to create a centralized health care system through the development of the AHCCCS model.

Since its inception, AHCCCS has provided persons eligible for Medicaid with medically necessary acute care services, preventive care services and a “medical home.” Primary care services for AHCCCS members are delivered by 12 private health plans and their provider networks located throughout Arizona. State officials note that 75 to 85 percent of licensed physicians and practitioners in Arizona participate in AHCCCS provider networks and, thus, Medicaid enrollees have an extensive network of primary care providers from which to choose (AHCCCS, 1997). Each recipient is linked to a primary care provider who is responsible for providing primary care services and arranging for referrals for specialty services. Primary care services covered under AHCCCS include all mandatory services required by the Medicaid agency under Title XIX, including physician services and Early Periodic Screening, Diagnosis and Treatment (EPSDT) services.

Although there are a large number of primary care providers participating in AHCCCS, key informants report that there is an insufficient number of primary care providers experienced in caring for CSHCN. Many parents interviewed felt that there are too few providers within AHCCCS that are capable of providing high quality, family-centered care to their children. In fact, they said that “some primary care providers have admitted to not being experienced enough or having the expertise in providing care for CSHCN.” However, key informants did note that there are a small number of primary care providers in AHCCCS who have a special interest in CSHCN from whom families feel they can obtain needed services for their child.

3. Specialty Care

As indicated earlier, the system through which specialty services are provided to CSHCN depends on whether or not the child has a CRS-eligible condition. For children who are not

---

4In rural areas of the state the choice may be more limited due to provider shortages.
eligible for CRS, specialty care services are provided through the AHCCCS health plan in which they are enrolled. Each health plan was described by key informants interviewed for this study as typically possessing a strong network of specialists and sub-specialists to provide services to their enrollees. While the specific makeup of these specialty care networks varies from plan to plan, the state does monitor that each plan has an adequate number of specialists enrolled in their networks.\(^5\) In order for a child to receive specialty care services a referral must be made by the primary care provider through the child’s health plan. Once the plan approves the referral, the child may receive services. However, key informants indicated that approval of these referrals often takes several days which can hinder the smooth delivery of services.

For those with CRS-eligible conditions, under the longstanding service “carve out” arrangement discussed above, AHCCCS health plans are required to refer children to the CRS program for their specialty care related to the CRS condition. This arrangement was designed to take advantage of CRS’ extensive experience in serving CSHCN through a multidisciplinary clinic model, as well as its historically strong relationships with private pediatricians. Those children who are eligible for CRS receive a wide range of surgical, medical, and therapeutic services from CRS’ multidisciplinary team of physicians, nurses, social workers, and other professionals such as audiologists and rehabilitative therapists.

Interviews with key informants revealed that this aspect of Arizona’s model was the subject of much controversial debate. Opponents of the carve-out, which included many AHCCCS officials, MCO administrators, providers, and even some parents of CSHCN, described problems that are commonly associated with such arrangements, namely confusion and disputes over boundaries (i.e., which system is responsible for providing and paying for which services) and concerns over inadequate cross-system communication (i.e., AHCCCS plans and CRS clinics not routinely and systematically sharing information and medical records pertinent to the children they are both serving). Some of the specific complaints lodged against the carve-out are described below.

\(^5\) Plans are currently required to report the maximum number of beneficiaries that a physician will accept, the total number of beneficiaries assigned to a plan, the physicians who are accepting new members, and specialty services that are available.
Some parents resented the rigid requirement that they obtain their child’s specialty care through CRS. Long waits for appointments in CRS clinics, inconvenient scheduling due to the considerable time that often exists between scheduled condition-specific clinics and, for some, long distance and travel times to receive care from one of CRS’ four clinics, were the most often cited complaints of parents.

CRS’ use of a condition-specific eligibility list caused confusion among some parents and providers; it sometimes seemed arbitrary to these individuals that some conditions suffered by CSHCN were required to be treated by CRS, while others were taken care of through the AHCCCS system. Furthermore, providers indicated that it was not always clear what specific array of services was “related” to the CRS condition and, therefore, the responsibility of one system versus the other. Providers admitted that, in some past cases, AHCCCS and CRS were guilty of trying to shift responsibility to one another for certain services.

Nearly everyone we interviewed agreed that insufficient information regarding the treatment of CSHCN was passing between the primary/acute and specialty care systems. AHCCCS administrators and providers complained of slow and/or overly detailed clinic reports from CRS (or of never receiving these reports at all), while CRS officials and providers, bolstered by the results of a recent medical record audit, claimed that their reports were forwarded to AHCCCS in a timely manner for the vast majority of children and that primary care providers simply did not use them or even realize they had them in their records.

Ultimately, AHCCCS officials, MCO directors, and plan providers questioned the need for maintaining what they saw as two parallel specialty care systems for CSHCN that actually use the same pediatric specialists to provide services. These informants clarified that AHCCCS health plans typically contract with the same physician providers as CRS. Thus, regardless of whether or not a child has a CRS-eligible condition, he or she is ultimately served by the same pool of providers, although not in the same setting as would occur through CRS.

Despite these issues, proponents of the carve-out, which included not only CRS officials and clinic staff, but also some providers and parents, were convinced that their traditional model represented the highest quality approach to caring for children with complex conditions and that keeping this system intact, alongside managed care, was in the best interest of CSHCN and their families. To these individuals, the setting and manner in which services are provided is the key; while AHCCCS plans might use the same physicians as CRS, they are not interested in, nor capable of employing the “one stop,” multidisciplinary team approach used by CRS, according
to some of the informants we interviewed. This approach, they believe, is far superior to the traditional medical system’s manner of providing treatment, which they characterized as fragmented, uncoordinated, and inconvenient for families.

The debates described above are not new. In fact, AHCCCS and CRS officials and providers have spent considerable time and energy in recent years exploring possible solutions to the challenges posed by the carve-out arrangement. These efforts are described in more detail in Section III.

4. Behavioral Health

Since 1990, behavioral health services for Medicaid eligible and certain other persons have also been provided through a service “carve out”. As mentioned previously, mental health and substance abuse services for AHCCCS enrollees are supported through a contract with the Department of Health Services which, in turn, subcontracts with five Regional Behavioral Health Authorities throughout the state. RBHAs receive capitated payments in return for managing all of the behavioral health care needed by AHCCCS enrollees. Services are rendered by a broad range of community-based providers under contract with the RBHAs, including hospitals, community mental health and substance abuse treatment centers, outpatient clinics, and residential treatment facilities. At the time of this writing, there were over 380 behavioral health providers associated with Arizona’s five RBHAs.

As indicated earlier, all Medicaid-eligible children are eligible for behavioral health services through the RBHAs. There is a standard eligibility, intake, and assessment process for everyone referred to a RBHA that must be completed before services can be delivered. Once individuals have completed the intake/assessment process they are sent to a behavioral health provider to receive services. The services provided through this behavioral health “carve out” include all mandatory Medicaid services under Title XIX, including inpatient hospital and psychiatric facility services, and several optional services including individual and family therapy, case management, and psychosocial rehabilitation. In 1997, over 22,000 children enrolled in AHCCCS received behavioral health services through the RBHAs.
Arizona has traditionally had problems in adequately treating persons with mental health problems for a number of reasons, including:

- **Shortage of providers.** Statewide shortages of mental health providers, generally, and a lack of providers experienced with caring for CSHCN with dual diagnoses, in particular, have plagued the RBHAs in their efforts to serve this population.

- **Limited treatment approach.** Many providers and parents interviewed for this study believe that the behavioral health “carve out,” while improving the identification and assessment of children with mental health problems, has not succeeded in improving the range and quality of care they receive. The capacity of the system is not sufficient to provide a full continuum of care in many parts of the state. In general, informants expressed concern that children are too often treated with medications for their diagnosed condition, rather than with therapy designed to address their problems in the context of their family and surrounding environment.

Within the context of managed care, the behavioral health carve-out has also challenged the system’s ability to provide integrated services. Even more than with the CRS carve-out, key informants stated that there were severe problems surrounding the lack of information exchange between the RBHA and AHCCCS systems. One informant said, “The two systems may be serving the exact same child, but neither will know what the other is doing. This can have very serious negative effects in, say, the area of prescription medication coordination.” Boundary problems between the systems also were cited; for example, pediatricians treating children with Attention Deficit Disorder were unclear about whether they could prescribe Ritilin or not, and many believed that policy dictated that all mental health related care had to be referred to the RBHA. Finally, key informants indicated that the RBHA assessment process is quite lengthy and that patients needing assessments must often wait weeks for an appointment. During this interim, according to MCO officials and providers, AHCCCS health plans are placed in the uncomfortable position of having to care for children that they don’t have the expertise to care for and/or rendering care to enrollees and incurring costs that may ultimately be disallowed, since they may appropriately fall within the responsibility of the RBHA.
Poor cross-system coordination was especially acute in the Phoenix metropolitan area (Maricopa County) in recent years, when an already challenging arrangement was exacerbated by the financial difficulties (and ultimate bankruptcy) of the area’s RBHA which led to a complete stoppage in service provision during parts of 1996 and 1997. However, a new contractor—Value Options—began managing service delivery in February 1999, and also instituted a number of strategies designed to improve communications with other systems of care. These include Client-focused Workgroups, where representatives from different agencies providing services to specific children or families come together to identify fragmentation and duplication in needed services; a Community Stakeholders Panel, consisting of various providers, consumers, agencies and other community members which regularly examine RBHA policies and operations and identify strategies for improved coordination; and a Mental Health Workgroup that brings together representatives of the various systems of care serving persons with Serious Mental Illness (SMI) and their families to develop cross-system service strategies to improve quality for the SMI population.

5. Case Management

Case management for CSHCN is essential for ensuring that these children receive the full range of primary, specialty, and other services they need in a coordinated and comprehensive manner. As discussed below, within AHCCCS, case management is provided to varying degrees by several systems of care utilized by CSHCN; however, no system is providing a truly comprehensive model of case management.

- **Primary Care Providers.** Primary care providers are the designated gatekeepers to the specialty care systems and are responsible for coordinating all services for their clients. In some cases, primary care providers that serve a large number of CSHCN have hired full-time nurse case managers to help coordinate care for their patients, but this is the exception rather than the rule.

- **Health plans.** AHCCCS plans employ a number of different types of staff to help to monitor and coordinate the care of their enrollees. Case managers and EPSDT Coordinators each work at either the system level to improve systems for referral and information exchange, or at the patient level to coordinate care (especially for those children using high levels of services and to facilitate the receipt of well-child services). However, these staff generally have large
caseloads and do not consistently provide intensive care coordination to all CSHCN in their plans.

- **CRS.** The CRS model coordinates the multidisciplinary care rendered within its specialty clinics, but nursing and social work staff do not typically have time to arrange and coordinate care outside of the clinic.

- **RBHAs.** The RBHAs are designed to provide case management based on the child’s level of functioning. Depending on the score they receive on their assessments, children are assigned to one of three levels of case management which varies in intensity in accordance with the needs of the child and family. However, this systematic design has not been well implemented; there was great consensus among key informants that the case management provided through the RBHAs was very weak and tended to focus narrowly on coordination within the mental health system.

As illustrated in the descriptions above, there is no overarching centralized system responsible for case management services for CSHCN enrolled in AHCCCS. Neither is there a single system that provides the intensive level of care coordination often needed by CSHCN and their families. Parents interviewed for the study expressed concerns about often having multiple case managers for their children, but still feeling that they were too often left to coordinate and obtain services on their own. While most parents felt that having one competent case manager coordinating all services for their children would be more beneficial than having several different case workers individually coordinating various clusters of services, others believed that having one case manager for each program that they worked with would be more beneficial, as long as the different case managers coordinated with one another to reduce fragmentation and duplication. Such coordination, however, was described as rarely occurring.

### B. Overview of ALTCS

Long-term care services for many of Arizona’s Medicaid beneficiaries are provided through the Arizona Long Term Care System (ALTCS), the state’s capitated program for developmentally disabled (DD) and elderly or physically disabled (EPD) populations—both of which include CSHCN—whose conditions are severe enough to put them at risk for institutionalization. It is overseen by the state’s AHCCCS administration, but managed on a day-to-day basis by the
Department of Economic Security’s Division of Developmental Disabilities (DDD) who is responsible for delivering all related services through an allocated budget by the Medicaid agency. Essentially, DDD serves as the single, centralized managed care entity for all ALTCS enrollees and is responsible for providing and arranging for the complete array of acute medical care, institutional, behavioral, home and community-based, and case management services needed by these enrollees. With its capitated payments, DDD directly manages the delivery of home and community based services (HOBS) and nursing home services to about 23,000 Medicaid-eligible individuals, including approximately 5,000 SSI disabled children (NACH, 1997). For these same individuals, DDD also subcontracts on a capitated basis with several AHCCCS health plans to provide primary and acute care. Similarly, the agency subcontracts with RBHAs to obtain behavioral health services for ALTCS enrollees.

The following sections will present detailed information on various aspects of the ALTCS model, emphasizing the extent to which the system provides a comprehensive integrated system of care for CSHCN.

1. ALTCS Eligibility

The ALTCS eligibility determination process is designed to maximize the number of individuals who qualify for the program. Services are provided to persons who are either elderly, physically disabled or developmentally disabled, and who pass both a financial and medical screen for the program (AHCCCS, 1997). Financial eligibility for the program is based on the individual’s income. The state has established ALTCS financial eligibility at the highest income amount permitted under federal law, which is 300 percent of the SSI eligibility level (AHCCCS, 1997). Ninety-two percent of the ALTCS population meet financial eligibility requirements based on the SSI criteria and the remaining 8 percent are eligible based on either AFDC or SOBRA poverty-level financial requirements (AHCCCS, 1997).

Once financial eligibility is established, a preadmission screen (PAS) is conducted by ALTCS medical assessors to determine if the individual is at risk of institutionalization in either a nursing facility or an Intermediate Care Facility for the Mentally Retarded (ICF/MR). Medical eligibility
for ALTCS is determined by two separate PAS instruments—one for the DD population and one for the EPD population—which use weighted scores to describe the functional, medical, nursing, and social needs of an individual (AHCCCS, 1997). Medical eligibility is determined by the actual score on the PAS. If a child does not score high on the PAS, they are not immediately denied; the assessor can refer the case to a physician for a final determination. Parents interviewed for the study perceived the application process for ALTCS to be very labor intensive because of the extensive amount of information required. On the other hand, interviews with ALTCS eligibility staff confirmed that eligibility determination is conducted systematically and consistently for all applicants and that the process produces a comprehensive assessment of each enrollee's needs, a report that subsequently allows the ALTCS managed care system to plan for and execute the delivery of a wide range of services in a controlled manner.

2. Primary and Specialty Care services

ALTCS offers a complete array of medical services which are integrated into a single delivery package coordinated by the Division of Developmental Disabilities. Once determined eligible, enrollees are linked with a “medical home”—a primary care provider who is responsible for providing or arranging for all medical care and related services. As indicated earlier, there are two separate populations served under ALTCS—the developmentally disabled population and the elderly, physically disabled population. Primary and acute medical services for the DD population are delivered through four of the 12 health plans that generally serve AHCCCS enrollees. These services for the EPD population are delivered via a network of program contractors located throughout the state. In addition, specialty care services for children with CRS-eligible conditions who are also in ALTCS are required to be referred to and provided by CRS. However, DDD officials report that very few DD children have CRS-eligible conditions and, therefore, the majority of their specialty care services are provided through AHCCCS health plans.

Primary and specialty care services provided by ALTCS include all mandatory services required by the Medicaid statute, all of the optional services covered under the AHCCCS acute care program, and several additional optional services, including habilitation, respite care, and
personal care services. For the most part, problems surrounding the provision of medical
services to ALTCS children are the same as those for other CSHCN enrolled in AHCCCS, such
as the limited number of primary care providers with expertise in caring for chronically ill and
disabled children and delays in the delivery of some specialty care services due to prior
authorization requirements. However, because ALTCS represents a centralized model with one
agency paid to manage the provision of all needed services, and because ALTCS also possesses
a strong centralized case management component (as will be discussed later), these issues
reportedly have not caused enrollees major problems.

3. Long-Term Care

In addition to acute medical care, ALTCS offers long term care services to eligible enrollees.
Institutional care is provided in either a Medicare/Medicaid approved nursing facility, hospice or
in an ICF/MR (AHCCCS, 1997). For enrollees who do not require the intense level of services
provided in an institutional setting, ALTCS also offers comprehensive home and community-
based services that are delivered in enrollees’ homes, hospices, child developmental foster
homes or other approved alternative settings such as behavioral health facilities. While other
states typically institutionalize the majority of their DD/EPD clients, Arizona serves more than
95 percent of these individuals in home and community-based settings (AHCCCS, 1997). In
making decisions about the best service delivery setting for each client, Arizona officials report
that the main objective is to keep clients at home as opposed to placing them in more costly and
restrictive institutional settings; to facilitate that goal, ALTCS funds the delivery of services
such as home renovation, medical equipment, respite care, and in-home habilitation (AHCCCS,
1997).

For the most part, ALTCS members receive care without restrictions on amount, duration, or
scope of covered services. Long-term care services covered under ALTCS include all
mandatory services required by the Medicaid statute, as well as several optional services
including home health agency services, developmentally disabled day care, and group respite
services. Once again, all long-term care services under ALTCS are directly managed and
provided by DDD through its network of providers.
4. Behavioral Health

As was the case with AHCCCS, DDD contracts with DHS to provide behavioral health services for ALTCS-eligible persons. DHS sub-contracts with the RBHAs and they, in turn, contract with networks of community providers to deliver behavioral health services. Eligibility requirements for behavioral health services under ALTCS are the same as those under AHCCCS—all Medicaid eligible persons under age 18, all SMI persons 18 years or older, and all non-SMI adults 21 years or older who have behavioral health needs are covered. Behavioral health services for ALTCS enrollees tend to be delivered in either inpatient hospital, or in community-based centers that provide group and/or family therapy and counseling. Key informants reported that the level of coordination between ALTCS and the behavioral health systems depends to a large degree on the level of experience of the DD case manager in coordinating services with the behavioral health system. (This will be discussed in more detail below.) Parents indicated that issues over whether needed services are DD or behavioral health-related can hinder the efficient delivery of services.

5. Case Management

In contrast to AHCCCS, where multiple systems each provided a limited form of care coordination to their clients, ALTCS utilizes a more centralized and comprehensive approach to providing such support to its enrollees, in particular the DD population.

All children enrolled in ALTCS are assigned to a case manager who is charged with providing an intensive form of case management and working to coordinate all aspects of care for the child. The DD population is assigned to special DD case managers who work to secure and coordinate services for these ALTCS-eligible children. In addition, each of the ALTCS health plans have DD liaisons who assist DD case managers in coordinating acute and specialty medical care for recipients on behalf of the plans, to eliminate any confusion over which providers are responsible for providing various covered services. Case management services are
also provided to the EPD population but are not as intense as those services provided to the DD population.

There are 400 DD case managers housed in the DDD whose services are coordinated through six district and 40 local offices. Each DD case manager oversees a caseload of 45 and is officially designated as the lead case worker for all services needed by enrollees. Responsibilities of the DD case managers include, but are not limited to, developing an Individual Service Program Plan, assisting enrollees in obtaining appropriate support and services, monitoring the provision and effectiveness of services, and providing information regarding services available from other state, community, and private agencies. The Individual Service and Program Plan (ISPP) which identifies support and services needed by the child, is developed in part by the PAS which is forwarded to DD case managers following the eligibility determination process. Services are provided based on the ISPP which is reviewed on a 90-day basis to determine additional service needs or changes in existing services. Although several weaknesses were identified by some key informants, including the tendency of DD case managers to focus more on HCBS than medical services, most felt that this form of case management allowed for a more comprehensive approach to care coordination, thus drastically reducing duplication and fragmentation of services.

D. Links to Other Systems

CSHCN who are enrolled in either AHCCCS or ALTCS are often involved with other systems of care to meet their health care needs; two prominent ones are the Early Intervention and Special Education systems. The remainder of this section will present information describing these systems in Arizona and the extent to which they are linked with AHCCCS and ALTCS.

1. Early Intervention

The Department of Economic Security’s Division of Developmental Disabilities (DDD), the same agency that administers ALTCS, is the lead agency for administering AzEIP, which offers
services to address the needs of developmentally delayed children ages birth to three. While
implementation of AzEIP services is overseen by DDD, responsibility is actually shared with
four other state agencies: AHCCCS, DHS, DOE, and the Arizona School for the Deaf and
Blind.

AzEIP has a universal application process. A child can enter the system through any of the five
agencies involved in its implementation, however, they need only to enter the system once.
Children may be referred for AzEIP eligibility determination by any concerned individual or
organization, such as parents, primary care physicians, providers, DDD or other agencies
(ADHS 1998). There are AzEIP intake service coordinators and developmental service
 coordinators throughout the state who together assess the child’s readiness for evaluation,
develop an evaluation/testing strategy, and help determine eligibility. Once eligibility is
determined and depending on the severity and types of needs he/she displays, one agency will
take the lead for service coordination, usually that which can provide the most services for the
child. Case coordination services for children in AzEIP varies depending on which agency is
taking lead; each of the five agencies will assume the primary coordinating role for a particular
subset of developmentally-related conditions, generally established by their own agency’s
 eligibility requirements, such as CRS for CRS-eligible conditions.

Services covered under AzEIP include assistive technology, infant massage, infant stimulation,
service coordination, play groups, speech language pathology, occupational and physical
therapy, and habilitation services. AzEIP services are provided based on an Individualized
Family Service Plan (IFSP) that is developed by a case manager together with the family for all
children from birth through 36 months who are at risk for or have developmental delays.

According to most key informants interviewed for this study, Part C/Early Intervention services
provided through Arizona’s Early Intervention Program (AzEIP) are strongly linked to both
AHCCCS and ALTCS as well as other systems as evidence by the following examples:

- Universal application. AzEIP has a universal application which allows a child
to enter the system through any of the five participating agencies (DOE,
AHCCCS, DDD, DHS, and the Arizona School for the Deaf and Blind). The streamlining of the application process for AzEIP has eliminated some barriers to services, including difficulty in accessing the system, and has enhanced the level of communication between participating agencies.

- **Centralized form of case management.** Under AzEIP, one agency is responsible for service coordination and the development of the IFSP. All enrollees are assigned a service coordinator within the lead agency who works with the other agencies to provide early intervention services for the child. Having a key person responsible for the coordination of early intervention services reduces fragmentation and duplication in services and helps to eliminate any confusion over which agency is responsible for providing various covered services.

- **Strong systems for referral and information exchange.** During the eligibility screening, parents are informed of available services for their child and are encouraged to apply for all appropriate services before eligibility is determined; thus, children are linked to other agencies even before they enter the system and parents become more aware of the functions and services provided by other agencies.

In addition, because DDD is the administering agency for ALTCS and the lead agency for AzEIP, the linkage between these two systems are further supported. For example, children 0-3 who are referred to ALTCS, are first sent to DDD to determine AzEIP eligibility. Once a child receiving AzEIP services reaches age three, he/she is referred to ALTCS for eligibility determination.

In the past, there has been some confusion over the provision of evaluation services by AHCCCS/ALTCS plans under AzEIP. The evaluation component of AzEIP services is to be covered under EPSDT by the plans regardless of eligibility. However, referrals to plans were being denied because plans perceived them as not being medically necessary. According to key informants, the agencies have been working to resolve these issues. With the help of AzEIP coordinators, plans and providers now understand the unrestrictive nature of services covered under EPSDT; thus denials have drastically been reduced.
2. Special Education

Special Education is overseen by the Arizona Department of Education’s Division for Exceptional Student Services and is provided to children ages 3 through 21 who have a developmental disability or present some type of developmental delay that affects their ability to learn. Services are provided based on an Individualized Education Plan (IEP) which is developed for each enrolled child and contains detailed information on services needed by the child. These services are generally provided to children with conditions classified under 12 disability areas established by the state, which range from autism and traumatic brain injury to specific learning disabilities and speech or language impairments. In order to receive special education services there must be a connection between the child’s disability and educational performance. Eligible children are linked to the system through AzEIP, teachers, parents or Child Find, an information and referral network established by the state to identify potentially eligible children for special education services.

There are 227 separate autonomous school districts and 220 charter schools in Arizona, each with its own governing board. An outgrowth of this autonomy is that there is considerable variation among special education programs in the many districts. Funding strategies for special education services vary among the school districts as well. Thus services range from the “bare bones” to very comprehensive in various districts, according to key informants. Special education services are typically extremely limited in rural areas of the state due to severe teacher shortages as well as overall statewide shortages in ancillary therapists.

DOE does not have a formalized relationship with either AHCCCS or ALTCS. Some informal relationships may exist, such as that between special education and the RBHAs, where RBHAs work with school-based mental health service providers to coordinate services, but only on an ad hoc basis. There is no interagency agreement that exists between DOE and AHCCCS for the provision of health services in the schools. Schools are permitted to bill Medicaid for medically necessary special education services, but they rarely do so. There are also no mechanisms in place for sharing information between health systems and schools regarding what services each are providing. Based on key informant interviews, it is apparent that there is a lack of
communication between Department of Education and other agencies serving CSHCN. Many felt that special education was in a system all by itself and the level of communication needed was just not there.

III. Lessons Learned Regarding Service Integration

Arizona’s Medicaid system for children with special health care needs is a complex one, characterized by two separate and distinct managed care models—AHCCCS and ALTCS. The diversity of these two models permits significant comparisons to be made with regard to service integration for CSHCN served by these two systems. This chapter will discuss some of the lessons that have been learned about how each model supports the goals of service integration for CSHCN and their families.

A. Systems for Identification, Eligibility, and Enrollment

Although there are many strengths in the Medicaid managed care systems in Arizona, significant room exists for improvements in the identification and enrollment of CSHCN into these systems. As mentioned in Section II of this case study, there is no formalized system for identifying CSHCN under AHCCCS, nor is there an attempt by AHCCCS to connect CSHCN with plans or providers that have special capacity or experience in caring for CSHCN. Families are simply given an application and information on the plans in their particular area. Once enrolled, CSHCN are not systematically assessed, nor flagged as having special needs unless he or she is referred from the CRS system as having a CRS-eligible condition. Thus, according to key informants, there is considerable concern that many children with special health care needs who are enrolled in AHCCCS are not routinely identified and, therefore, may not receive the comprehensive services they need.

ALTCS, on the other hand, has a systematic approach to identifying eligible children. As discussed in Section II, ALTCS eligibility staff conduct intensive assessments of need, and the results of these assessments are used to help develop the enrollees care plan and to assign
children to case managers. While, unfortunately, this process was described as long and often “overwhelming” for parents, key informants expressed the sentiment that the benefits of collecting medical information and assessing needs, in terms of organizing the delivery of comprehensive services, far outweighed the costs.

B. Cross Systems Information Sharing and Integration

Information sharing is a critical component of a coordinated and integrated system of care for CSHCN because it allows systems to be aware of the functions and services provided by other agencies, thereby enhancing the capacity of those systems to provide coordinated services to their clients. However, poor information flow and lack of coordination across the various agencies serving CSHCN was consistently described by key informants as a critical weakness of the AHCCCS model. The two major “carve out” arrangements used by AHCCCS—for CRS and behavioral health services—were identified as the structures that were at the root of these problems. By separating large clusters of services from the responsibility of AHCCCS plans, policymakers have “built in” problems related to information exchange, unclear boundaries of responsibility, and coordination challenges, according to many administrators and providers interviewed for this study. Many of these individuals believed that insufficient policies and program mechanisms existed within AHCCCS to dictate clear divisions of responsibility among the systems and to support the free flow of information between system providers; these conditions were described as significantly undermining the ability of AHCCCS to provide integrated services to CSHCN.

In contrast, the ALTCS model was described as more effective in supporting strong information exchange and the delivery of integrated care among providers serving CSHCN. This was attributed to several design factors that facilitate communication between system components, as described below.

- A single agency being accountable for all care. Under ALTCS, no services are “carved out;” rather, the DDD is paid and responsible for assuring that all ALTCS eligible persons receive the full range of services they need. While DDD subcontracts with many of the same systems for the delivery of care to ALTCS
enrollees (e.g., AHCCCS health plans for acute care, CRS for CRS-related care, and RBHAs for behavioral health services), it still maintains a centralized authority and fiscal responsibility for managing all service delivery. This authority has supported the model’s ability to set consistent policy, address coordination issues, and resolve problems in a consistent manner.

- **Centralized case managers.** As the single agency responsible for the care of its enrollees, ALTCS has developed a centralized case management system. All enrollees are assigned a case manager, based on level of need, and these providers work to coordinate the delivery of multiple services for recipients. Having a designated point person in this role was described as supporting the more integrated delivery of care for CSHCN.

- **DD Liaisons.** Each of the AHCCCS plans that subcontract with ALTCS have designated DD liaisons who assist the DD case managers in coordinating the medical care of ALTCS enrollees. This formal mechanism provides a means by which confusion or disputes over service delivery among system providers can be directly addressed and resolved.

Each of these mechanisms are set in place to help ensure the adequate flow of information among system components and the coordination of the care they deliver.

**C. Systems for Service Coordination**

Because CSHCN often require a complex level of care from a multitude of systems, strong systems for care coordination are essential. Arizona’s AHCCCS and ALTCS models offer interesting lessons about the pros and cons of the different approaches to service coordination.

As noted previously, many delivery systems involved with AHCCCS provide case management, but not in a manner that looks at service coordination across systems, nor that provides intensive support to those children and families that need it. No single centralized system or agency is responsible for case management for CSHCN enrolled in AHCCCS, thus, the level of case management these children receive varies depending upon the systems in which they are enrolled. Most key informants interviewed for the study felt that the case management provided under AHCCCS was spotty, at best, and that the lack of a more systematic approach for CSHCN severely undermined the program’s ability to provide truly integrated care. Parents felt...
that they bore the greatest burden for this lack of systematic coordination, as they were left with ultimate responsibility for navigating systems and arranging the care their children needed.

In contrast, children enrolled in ALTCS receive a more consistent and intensive version of case management, it seems. Each child in the system is assigned a case manager that is charged with coordinating all aspects of care needed by the child. This model, while not perfect according to key informants, at least is designed to limit duplication and fragmentation of effort.

D. State Level Coordination Efforts

To their credit, Arizona officials are fully aware of the coordination problems that exist in their models for serving CSHCN and have worked hard to address and resolve them. Various interagency committees, councils and work groups have been established at various points to identify and analyze areas where fragmentation and duplication of services exist, and to develop strategies for resolving them.

Of particular relevance are Arizona’s efforts to maintain a high level of communication and collaboration between AHCCCS, ALTCS, and CRS. The agencies work closely together to identify areas where improvement is needed. For example, the AHCCCS and CRS agencies have in the past established workgroups to revise CRS eligibility standards, enforce EPSDT rules, and address the needs of SSI beneficiaries. Recently, AHCCCS, ALTCS, and CRS staff have developed several new initiatives, including the Interagency Case Management Project (a project piloting case management services between several agencies for children with severe emotional disabilities); the Interagency Collaboration Committee (established to work on streamlining services for CSHCN); and the Standards and Eligibility Project (to bring all systems and agencies together to set up universal eligibility guidelines for CSHCN).

In addition, challenges surrounding service coordination and integration prompted CRS and AHCCCS officials to develop in 1997 a CRS Transition Planning Project. This project was initiated to consider alternative approaches to transferring administrative and programmatic
responsibility for CRS from DHS to AHCCCS, in an effort to resolve service coordination problems between the two agencies while enhancing services for CSHCN (ADHS, 1999). After lengthy debate and analysis, it was determined that CRS should not be transferred to AHCCCS. Instead, a number of recommendations of the Transition Planning Committee should be implemented to strengthen the CRS program’s ability to provide services within the AHCCCS model. For example, CRS staff have nearly completed an analysis to determine which CRS-eligible conditions truly require the multi-disciplinary team approach used by CRS clinics and which can be adequately served in traditional medical settings. This study may hold important implications for how services across these two systems will be integrated in the future.

Another example of strong interagency coordination in Arizona can be seen in the Governor’s No Wrong Door initiative, which represents an effort by a specially appointed interagency committee to develop a universal, cross-system application for all of the state’s children’s programs. Recent demands by consumers to have a more simplified enrollment process for AHCCCS and other programs serving children served as the impetus for this effort, the outcomes of which could especially enhance the experiences of CSHCN and their families in need of services from multiple systems and programs.

E. Family Involvement in System Planning, Implementation, and Oversight

While it is clear that Arizona’s managed care systems possess critical weaknesses with regard to coordination and integration of care for CSHCN, it is equally clear that Arizona officials have worked hard to keep families and families’ needs at the center of their policy decision making. The Department of Health Services’ Title V program, in particular, has a long and impressive track record for involving parents of CSHCN in system planning, implementation, and oversight efforts. Its Office of Children with Special Health Care Needs (OCSHCN) works on a broad level to develop comprehensive systems of care for CSHCN through such activities as its Community Development Initiative, through which parent leaders facilitate and support desired community change through Community Action Teams. Similarly, Project Tsunami represents a statewide advisory group composed of parents of CSHCN who participate in policy and
program work groups and advocate for other families in support of local efforts to create stronger family/professional partnerships. OCSHCN has also worked to establish strong linkages with other programs serving CSHCN, including AHCCCS and AzEIP, to help ensure that families remain the focal point of their systems.

However, despite these numerous efforts, it appears that the managed care systems that have emerged over time in Arizona are not family-centered. With AHCCCS, in particular, parents we interviewed described how confusing the system was, how difficult it was to negotiate, and how much burden fell to them to orchestrate the delivery of services needed by their children. The system’s weaknesses with regard to service integration appear to have a particular negative impact on families with CSHCN who need such a broad array of services from such a diverse set of systems.

F. Conclusion

Arizona has developed an innovative yet complex Medicaid managed care system which includes two very distinct and contrasting models of care for CSHCN. Based on our interviews with key informants and parents, AHCCCS appears to succeed well in providing a medical home to all its enrollees, but falls short in providing integrated and coordinated services to children with special health care needs. A single agency being accountable for all care, centralized case managers, and program liaisons, which are key design strengths of ALTCS, are not integral to either CRS or BHS.
References:


Appendix A: Key Informant List
Appendix A: Key Informant List

The following persons were interviewed by researchers of the National Policy Center for Children with Special Health Care Needs in their study of Arizona’s Medicaid managed care system for CSHCN:

Arizona Health Care Cost Containment System:
- Juman Abujbara

Children’s Rehabilitative Services:
- Susan Burke
- Cathryn Echeveria

St. Joseph’s CRS Clinic:
- Dr. Susan Gregg
- Donald Graf
- Ann Chase
- Maggie Haugen
- Debra Leach

Division of Developmental Disabilities:
- Ida Fitch
- Brian Lench

Raising Special Kids:
- Betsy Trombino and parent advocates

Phoenix Pediatrics:
- Dr. David Hirsch
- Diana Frieberg

Arizona Long Term Care System Medical Eligibility:
- Diane Harper
- Dick Yanno
- Sylvia Lee
- Mike Swerski
- Steve Chiles

Arizona Physicians IPA:
- Dr. Leonard Tamsky
- Mary Beardsley
- Penny Brand
- Connie Williams

Division of Behavioral Health Services:
- Valinda Mores

Department of Education:
- Rita Kenison

Value Options:
- Helen Hayes Sommer

Mercy Care:
- Kathy Byrne
- Helen Hoiser
- Marty Miracle
Case Study: District of Columbia

I. Background and Introduction

Like most other states around the country, the District of Columbia has been actively developing managed care systems for Medicaid recipients in recent years. While working to establish a mainstream managed care system for persons eligible for Medicaid through the Temporary Assistance to Needy Families (TANF, the former Aid to Families with Dependent Children) program, the District has also developed a special managed care system for children with special health care needs (CSHCN). In October 1995 the District gained national attention when it received approval from the federal Health Care Financing Administration (HCFA) to implement a new 1115 waiver program designed to provide comprehensive care on a fully-capitated basis to children eligible for Medicaid through the federal Supplemental Security Income (SSI) program. This case study provides an overview and assessment of this “specialized” managed care model designed to meet the needs of CSHCN and their families.

A. Medicaid Managed Care and CSHCN

The origins for the District’s Medicaid managed care network for children with special health care needs (CSHCN) began in 1993 when officials from the Hospital for Sick Children, a long-term care and rehabilitation facility in Washington, DC, developed the idea for the program. Their idea was an outgrowth of several factors, namely the development of Medicaid managed care systems in the District, families’ reports of uncoordinated care in those systems, and the lack of waivers in the District to allow chronically ill children to be cared for in their homes and communities rather than in institutions. Hospital officials proposed to District Medicaid officials that the District and the Hospital enter into a public-private partnership to develop a managed care network specifically designed for CSHCN. Medicaid officials agreed and, working closely with Hospital officials, developed and applied for a waiver from HCFA to establish the program. Two and a half years later, in 1995, HCFA granted the waiver.
Given the central role of the Hospital for Sick Children in the conception and development of the idea for the network, the District’s Medicaid agency was committed to working with the Hospital and its umbrella organization, the Hospital for Sick Children Foundation, to implement the waiver program. In order to avoid any conflict of interest in running the program, the Hospital and the Foundation created an independent private non-profit corporation called Health Services for Children with Special Needs, Inc. (HSCSN), with which the District’s Medicaid agency entered into a three-year sole source contract. The District’s decision to use a sole source contract and forego a competitive bid process led several well established CSHCN providers in the District, especially day treatment providers, to shun the program in its early phases. However, most of these providers have ultimately elected to participate, and the plan has succeeded in creating a comprehensive network of providers to serve its enrollee population.

As the waiver program is targeted to children on SSI, many of the District’s Medicaid-enrolled CSHCN who do not meet SSI eligibility criteria have been unable to participate. Instead, these children and their healthier counterparts have been enrolled in the mainstream managed care system that the District has been in the process of implementing over the past several years. All TANF-related Medicaid beneficiaries have been enrolled into capitated managed care plans.

B. Structure and Approach to State Site Visits

The information presented in this case study is based on interviews that researchers from the National Policy Center for Children with Special Health Care Needs conducted during the latter half of 1998. Specifically, the researchers interviewed a range of District officials, public and private providers, and parents through both telephone and in-person interviews, as follows:

- In the summer of 1998, researchers conducted extensive, structured telephone interviews with state Medicaid and Title V officials regarding the development, implementation, and operational experiences of its managed care network for SSI children. These interviews set the stage for and helped to structure follow-up meetings with additional informants to obtain further information about the HSCSN and related systems.
During the fall of 1998, the same researchers conducted numerous in-person and telephone interviews with individuals and small groups representing HSCSN, the District’s Commission on Mental Health Services, and Part C/Early Intervention Program, as well as parents of children with special health care needs. (A list of interviews is included in Appendix A.) Each of the interviews was guided by one of several structured protocols targeted to the particular orientations of the interviewee.

C. Organization of Report

The remainder of this report is divided into two sections:

- Section II provides a detailed summary of the structure and operation of the District’s network for children on SSI operated by HSCSN, including a discussion of systems for eligibility determination, identification, and enrollment; primary care; specialty care; case management; and the range of other services provided by the program and related systems of care.

- Section III discusses the lessons that have been learned by District officials, providers, and families during the implementation of the HSCSN network. Lessons regarding the development and operation of a comprehensive model for chronically ill and disabled children, such as those related to identification of CSHCN, financing, family involvement, and executive-level interagency coordination, are discussed.

II. The Model

Compared to most of the states studied under this project, the District’s Medicaid managed care model is distinguished by its specific design to serve CSHCN and for its operation through a single private, non-profit entity, HSCSN. This section details information regarding the structure and operation of this specialty model.

A. Overview of Model

The District of Columbia’s managed care network for children with disabilities was designed as a comprehensive system through which SSI-enrolled children can receive all of their needed
health and health-related services in a coordinated manner. Children on SSI have the option of voluntarily enrolling in the plan or, alternatively, remaining in the traditional Medicaid fee-for-service system. (Children on SSI are exempt from the District’s mainstream managed care program.) The program operates under a Section 1115 demonstration waiver from the federal government. The original waiver was approved for a three-year period—from December 1995 to November 1998—and HCFA recently granted the District a one-year extension through November 1999 to keep the program in place for another year before the contract is rebid.⁶

To implement the waiver program, the District contracted with one private non-profit managed care plan, HSCSN, to provide services for children on SSI. HSCSN, in turn, contracts with a broad array of providers throughout the District and surrounding suburbs to provide services to plan enrollees. The plan, commonly referred to as “the Net” by DC officials, providers, and parents, covers a comprehensive array of services for children, including primary and specialty medical care, mental health, substance abuse treatment, and a broad range of ancillary and support services through contracts with area providers. Outreach and case management are also provided to all Net enrollees by in-house staff.

Medicaid provides the plan with a standard capitated payment of approximately $1,000 per member per month. This rate, which was developed based on historical fee-for-service cost data for Medicaid children on SSI, is equivalent to 97.5 percent of the average payment for people on SSI receiving Medicaid services. (Before permitting the District to implement its waiver, HCFA required that the District get this rate approved by both the U.S. General Accounting Office and the federal Office of Management and Budget.) While Medicaid pays HSCSN through a capitated arrangement, the plan reimburses its contracted providers on a fee-for-service basis. To protect against the plan experiencing significant profits or losses resulting from unanticipated expense patterns, “risk corridors” are in place such that the plan shares

⁶Unlike its relationship with HSCSN, which was established through a sole source contract, the District’s Medicaid agency plans to release a competitive Request for Proposals to the broader community for the next cycle of its waiver. Ultimately, it hopes to establish contracts with at least two specialty managed care plans.
profits and losses with the District’s Medicaid agency.\textsuperscript{7} During its first year of operations, the Net earned substantial profits and, therefore, had to repay a portion of its fees to the District government.\textsuperscript{8}

B. Eligibility, Identification and Enrollment

As described above, DC’s specialty managed care model for CSHCN targets a narrow subset of this diverse population—children eligible for SSI. While recognizing that many additional CSHCN do not meet the narrow criteria for SSI eligibility, Medicaid officials decided to target the program to this clearly-defined subset of the population for a variety of practical reasons, including the straightforward nature of determining if a child is eligible for the program, the corresponding administrative simplicity of operationalizing this approach, and the availability of cost data for this group under the fee-for-service system with which to develop reliable capitation rates.

In designing the waiver program, Medicaid officials envisioned mandatory enrollment of all SSI-enrolled children into the managed care system. Officials believed that this feature would help ensure that the plan would enroll and serve a broad range of clients, and reduce the potential for adverse (or favorable) selection. In reviewing the waiver application, however, federal officials determined that it was not appropriate to limit SSI eligibles’ free choice of providers and required that the waiver employ voluntary enrollment.\textsuperscript{9}

\textsuperscript{7}Risk corridors have been established around an 85 percent medical claims ratio (defined as plan costs divided by Medicaid payments). At 85 percent, there is no cost sharing. Gains or losses are split between the plan and the Medicaid agency.

\textsuperscript{8}Financial reconciliation, the method through which it is determined if the HSCSN plan owes money to or is owed money from the Medicaid agency, had at the time of this study only been conducted for the plan’s first year of operations. Thus, it was not known how the plan performed financially for subsequent years of the demonstration period.

\textsuperscript{9}During the waiver’s next cycle, DC Medicaid officials hope to revisit this issue and request permission to make enrollment in the Net mandatory for all children on SSI. In addition, now that it has several years of experience administering the waiver, Medicaid is considering adding foster care children to the list of those CSHCN eligible for enrollment in the Net.
To notify families with children on SSI about the opportunity to enroll in the specialty network, the Medicaid agency mails families a packet of information about their option to either enroll in the plan or stay in the fee-for-service system. Parents are asked to return a signed enrollment form if they want their child to participate in the plan. The only children who are enrolled are those whose parents make an active decision for their child to participate, as evidenced by their signed enrollment choice form. Families that do not actively select to participate in the waiver program remain in the traditional fee-for-service system.

While Medicaid does not automatically assign children to the HSCSN plan, it does allow direct marketing by the plan to all families who have not made an enrollment decision within 45 days. The plan is barred from offering outright incentives to enroll, however, HSCSN may send a plan representative to meet with non-responding families to discuss the information package they received and to assist the family in deciding whether enrollment in the plan or staying in fee-for-service best meets their child’s needs. During the waiver’s first enrollment period, very few families—less than 10 percent—returned the enrollment form within the prescribed 45-day time frame. In response, the plan hired a large staff of outreach workers from the community and conducted an extensive outreach effort to find and speak with families about their enrollment options. These outreach workers have been instrumental in bolstering participation rates in the Net; Medicaid now reports that between 80 percent and 90 percent of families with SSI children that meet with a plan representative ultimately decide to enroll in the plan. In total, roughly 2,000 of the District’s 3,000 children on SSI, or two-thirds of the eligible population, are now enrolled in HSCSN. Considering also that DC officials cannot locate nearly 700 children on SSI reportedly living in the District, the plan’s outreach efforts have apparently been very successful.

C. Primary Care

Recognizing the importance of regular preventive and primary care for all children, the District’s Medicaid agency and HSCSN have made primary care the centerpiece of this program for CSHCN. Under its contract with the District, HSCSN is responsible for covering all Medicaid services to plan enrollees according to the rules and regulations embodied in the Early
and Periodic Screening, Diagnosis, and Treatment (EPSDT) program. Thus, HSCSN is required to follow EPSDT’s periodicity schedule for routine screening, and to use the results of EPSDT screens as the basis for every child’s plan of care. This approach is designed to ensure that all enrolled children receive appropriate primary care services.

The HSCSN network includes more than 100 primary care providers to serve its 2,000 enrolled children, resulting in a patient-to-provider ratio that program officials indicate is significantly more favorable than that available under mainstream managed care. Generally, pediatricians, internists, and family providers serve as primary care providers, although specialists may also do so if they provide primary care services including immunizations.

Interestingly, however, despite the plan’s strong emphasis on well-child care and the significant numbers of primary care providers enrolled in its network, HSCSN has experienced many of the same problems that fee-for-service systems have traditionally experienced in encouraging utilization of preventive screening services. This illustrates the continued need for education about the importance of primary care and other creative approaches for linking CSHCN to primary care services.
D. Specialty Care

Given the complex and diverse needs of chronically ill and disabled children, a provider network of appropriate breadth and scope represents one of the most critical features of any managed care plan intending to serve CSHCN. With its network of nearly 2,000 providers, a large proportion of whom are specialists, HSCSN has certainly distinguished itself in this regard. The plan’s enrolled providers include a complete panel of pediatric subspecialists, including pediatric cardiologists, neurologists, nephrologists, psychiatrists, psychologists, neurosurgeons, and others specializing in the care of children with special needs. In addition, HSCSN has contracted with the full range of provider types that have traditionally served Medicaid-eligible CSHCN, including all of the District’s hospitals with pediatric capacity, Title V-supported public health clinics,10 therapeutic day care providers, behavioral health/substance abuse treatment programs, home health agencies, rehabilitative and rehabilitative therapists, counselors, and suppliers of durable medical equipment. The plan has also reached beyond these traditional providers to include providers of non-medical services commonly needed by CSHCN and their families, including home modifications, transportation, mentoring, and limited access phone service.

According to program officials, the plan’s success in enrolling such a large number and broad array of providers can be largely attributed to two factors.

- First, HSCSN reimburses providers at rates equal to or greater than those paid by Medicaid. Early in the waiver’s implementation, HSCSN determined that traditional rates paid by Medicaid were typically too low to provide primary care physicians, dentists, psychiatrists, and others with the appropriate incentives to render high quality care to this complex population. Therefore, it set rates significantly higher than Medicaid’s, and the response from the community’s providers was very positive. (The exception to this policy is with rates for pediatric specialists; HSCSN’s rates are the same as Medicaid’s since they were judged to be quite fair and competitive with the private sector.)

---

10 Currently, approximately 80 percent of the District’s Title V block grant funds are earmarked for clinical services to low-income residents, including CSHCN. Title V public health clinics’ enrollment as specialty providers in the HSCSN network marked the first time the Title V clinics have been contracted as providers with a managed care plan.
Second, the plan processes claims much more quickly, and thus pays providers in a more timely manner, than the Medicaid agency.

These factors have played a significant role in encouraging providers’ participation in the network and, perhaps just as important, their receptivity to having their patients enroll in the plan. As a result, HSCSN has succeeded in creating a specialty network that is, according to key informants interviewed for this study, far better equipped to serve CSHCN than those typically found in mainstream managed care plans. In turn, due to the extensiveness of the network, informants indicated that it is often easier to get a timely appointment for specialty services through the HSCSN network than through plans with a more limited base of specialty providers.

The plan has also facilitated children’s access to needed care by addressing a common consumer complaint about mainstream managed care—the need to obtain multiple prior authorizations in order to receive specialty services. As will be discussed in more detail below, HSCSN allows each child’s plan of care, developed by the plan’s case managers, to serve as preauthorization for identified needed services for a period of six months, after which time the plan of care is reviewed and updated. Parents of enrolled children reported that this approach has helped reduce the burden related to obtaining individual prior approvals for specialty services needed by their children.

E. Case Management

Reflecting observations often ascribed to case management, key informants interviewed for this study described case management as the “glue” in the system of care for CSHCN provided by HSCSN. More specifically, case management was described as HSCSN’s key strategy for ensuring that children receive the full range of primary, specialty, and other needed services in a coordinated and family-friendly manner. Case management and its close counterpart, outreach, are the only services that are provided directly by HSCSN; a large portion of the plan’s approximately 40 employees is composed of its in-house case management and outreach staff.
The case management approach implemented by HSCSN is comprehensive. Before a new enrollment can be processed, the client must receive an initial home visit during which an extensive risk/needs assessment is performed. This assessment reviews the physical, social, environmental, and psychosocial factors that may be affecting the child and family. Results of the assessment are then shared with a multidisciplinary team that includes the care manager, family members, and providers who, together, develop the child’s plan of care. (This plan, as discussed above, serves as the patient’s preapproved referral for specialty services for a period of six months.)

Each client is assigned to one of HSCSN’s four case management teams, each of which includes a mix of three staff levels who provide varying levels of case management services, as described below:

- **Team leader.** Team leaders hold a masters in a health field; two of the four team leaders are nurses, and two are psychiatric social workers. Team leaders serve as the lead care manager for clients with the most intensive needs, such as transplant candidates, children on respirators, and paranoid schizophrenics. In addition, they supervise the other staff on the team and review the care plans for all the children assigned to the team.

- **Care managers.** Care managers are licensed in the health care field and may or may not have a masters degree. These staff provide a mid-range intensity of case management services. Children who would be assigned to care managers as their primary contacts include those with cerebral palsy and children with attention deficit disorders also experiencing depression and/or problems in school.

- **Care manager associates.** Care manager associates hold a health-related degree but are not necessarily licensed. They provide case management services to children with the least complex problems, such as those with attention deficit disorders.

The assignment of the client to a particular team and primary contact within that team depends on the child’s primary condition and the functional status of the family. For example, children whose primary diagnosis is psychiatric in nature would be assigned to one of the two teams headed by a psychiatric social worker, whereas children with complex medical problems would be assigned to a team headed by a nurse. Within that team, children who require a more
intensive level of case management are assigned either a care manager or team leader as their primary contact, whereas those who require minimal support would be assigned to a care manager associate. While children remain on the same team throughout their enrollment in the plan, their primary contact within that team may change to a staff member who provides a more or less intensive level of case management in accordance with their changing needs.

Regardless of the level of case management being provided, all case managers participate in a similar set of activities. In addition to the initial development and periodic review of care plans, case managers also provide ongoing monitoring and facilitate access to the services outlined in the child’s plan of care. This support often takes the form of scheduling and reminding clients about appointments, arranging transportation, communicating and coordinating with case managers in other public systems (e.g., foster care, schools/special education), and providing emotional support to families. Depending on the level of need exhibited by each family, case managers provide more or less intensive levels of care corresponding to one of the three levels of case management established by HSCSN administrators. In contrast to the initial home visit, most of the ongoing contact between case managers and clients occurs by phone. To facilitate this contact for the many clients who do not have phone service, the plan often pays for the installation and costs of local phone service. This benefit is highly valued by the plan’s low-income enrollees.

F. Support Services

In addition to a broad range of primary and specialty services, HSCSN also uses its capitated reimbursement to cover a range of nontraditional support services frequently needed by these children and their families. As indicated above, HSCSN will cover basic phone service for families without phones and, in addition, pays and arranges for transportation to medical appointments, both of which are reported to be big “drawing cards” for families with limited resources. The plan also provides mentoring services and therapeutic day care, camps, and after-school programs, as well as programs to address the needs of at-risk teenage enrollees.
For example, the plan contracts with a local AIDS clinic to provide counseling in sexual issues for enrollees at high risk for contracting sexually transmitted diseases.

Other support and wrap-around services provided by the plan include translation services, family counseling and, of particular importance to families responsible for the extra demands of caring for a special needs child, respite services (the plan will cover 120 hours every six months). The plan’s coverage of these types of services is another important way that the plan has distinguished itself from mainstream managed care systems.

G. Mental Health

Interviews with HSCSN representatives revealed that children enrolled in the waiver program have a surprisingly high level of need for mental health services. In fact, plan officials indicated that more than half of enrollees have psychological or behavioral health problems, most commonly learning disabilities, attention deficit hyperactive disorder, and other behavioral challenges.

The HSCSN plan was conceived and structured as a program for children with physical problems as their major health challenges, and was initially ill-prepared to address the high level of need among enrollees for mental health and behavioral services. However, the plan has used the flexibility afforded by its capitated payment arrangement with Medicaid to fashion a number of creative service interventions, such as covering fees for camps for troubled children, providing day treatment for children needing psychological care, and linking disadvantaged youth with mentors. To address the particularly intense needs of certain enrollees, the plan has also provided such crisis interventions as 24-hour care for children at risk of imminent danger to themselves or others, such as children with abusive parents or those with a strong likelihood of hurting others. For example, the plan provides escorts for children with serious emotional disturbance who are being transported by air to out-of-state treatment facilities and pose a danger to other passengers or the pilot.
Both plan representatives and officials of DC’s Commission on Mental Health Services stressed the importance of closely coordinating physical and mental health services and service delivery systems, as the same children often exhibit needs in both areas. In the case of this managed care model, this philosophy has been operationalized by having HSCSN assume responsibility for coordinating and directly providing all of the physical and mental health services needed by its enrollees. Due to a variety of factors—including the limited capacity of the District’s public mental health system to meet the demand for services; the targeting of most public mental health dollars and services to adults; and the more focused orientation of the HSCSN program to special needs children—the public mental health system is not used by HSCSN. Indeed, this system routinely refers all of its SSI-enrolled children to HSCSN for their care. For now, the physical and mental health needs of HSCSN enrollees appear to be met well by this arrangement. However, the District’s broader system of care for CSHCN could be significantly improved through better coordination between HSCSN, Medicaid, and the District’s mental health agency for children.

H. Early Intervention

Ten percent of the children enrolled in the HSCSN program are under age three; these children account for approximately half of the children served by the District’s Part C/Early Intervention program. As described by key informants, Part C-eligible children who are enrolled in HSCSN typically have all of their service needs arranged and paid for by the plan. Similar to the arrangement between HSCSN and the mental health system described above, the District’s early intervention system typically defers to the waiver program for the care of children dually enrolled in HSCSN and Part C. In light of the Part C program’s extremely limited resources, its role as payer of last resort after Medicaid, and the successful track record of the HSCSN plan in serving its clients, Part C officials consider this course of action to be both appropriate and resource efficient from the program’s and client’s perspectives. It also frees up resources that would otherwise be spent on services for children in the waiver program to enhance early intervention services for children enrolled in mainstream managed care plans.
That HSCSN has been able to afford the costs of early intervention and mental health services for its enrollees is a reflection of the current generous level of payment the plan receives from the Medicaid agency. However, according to HSCSN administrators, the ongoing capacity of the plan to continue to pick up costs for which other public systems may be responsible will depend on several factors, including the successful maintenance of current capitation rates with the Medicaid agency, and a stable case mix of children with needs comparable to those currently exhibited.

As was the case between the plan and the children’s mental health system, as well as other public systems of care important to special needs children, HSCSN had been working on developing more formal and systematic referral and cost-sharing arrangements with Part C and other agencies, but staff changes at the plan disrupted progress in this area. Discussions have reportedly recently been re-established toward this end.

I. Special Education Services

Under its contract with Medicaid, HSCSN is not responsible for paying for special education services. Special education services are to be arranged by the schools and, for those children insured by Medicaid, schools are to directly bill Medicaid. Medicaid, in turn, reimburses schools for covered special education services on a fee-for-service basis. For reasons similar to those discussed above for the mental health and early intervention systems, however, these services are also often covered by HSCSN for children enrolled in the plan.

Accounts by key informants and recent newspaper articles on the topic consistently describe the District’s special education system as being in serious disarray. There are lost wait lists of children waiting to be assessed for special education needs, and even for those children who are determined eligible and have Individual Education Plans (IEPs) developed, the District’s schools have a poor track record in delivering services identified in children’s IEPs. For these practical reasons, HSCSN has chosen to cover and absorb the costs for many of the services required by children eligible for special education. Individual HSCSN case managers, however, work hard
to establish and maintain relationships with school case managers and teachers, and parents report their children have benefitted from these relationships. However, formal agreements between the HSCSN plan and the District’s Department of Education to promote high-level and systematic coordination between the two systems do not currently exist and would certainly help to extend such benefits to more children.

III. Lessons Learned Regarding Service Integration

The District of Columbia’s Medicaid managed care program for CSHCN represents an intriguing model for policymakers interested in fostering comprehensive and coordinated systems of care for special needs children. The District’s three years of experience in serving SSI-enrolled children through its specialty plan provides an important foundation upon which to continue to improve its own systems of care for CSHCN as well as an important source of insight to other states working to better serve Medicaid-eligible CSHCN. Specific lessons learned regarding the ability of the specialty network model to facilitate service integration, as well as lessons related to financing, identification and enrollment, family involvement, and interagency coordination are detailed below.

A. The Model and Service Coordination

For children who are eligible for SSI, HSCSN offers a unique system of care with many important benefits. As a program designed specifically to meet the needs of chronically ill and disabled children, the waiver program offers a responsive alternative to the mainstream managed care system, which is designed primarily to serve a healthier population.

More specifically, the plan has several key features which not only work on their own to meet the special needs of these children but also work together to foster the delivery of comprehensive and coordinated services. These features, as discussed above, include:
Comprehensive case management services. Case management is a central feature and key strength of the HSCSN plan. The plan links all enrolled members with a case manager who conducts a comprehensive assessment of family risks, oversees the development of an individualized care plan, assists families in getting children needed services through such activities as arranging transportation, scheduling appointments, monitoring that well-child exams and immunizations are received, facilitating referrals for services, and providing support to families. Case managers also play a critical role in communicating and coordinating with other systems of care serving enrolled children, such as the special education and foster care systems. The activities of case managers are critical in facilitating an integrated approach to meeting each child’s complex health and related support needs.

Extensive provider network. The HSCSN network includes approximately 2,000 providers to serve the plan’s 2,000 enrollees. This unusually high provider-to-patient ratio has supported enrollees’ good access to needed care. The fact that the network seeks out providers who are knowledgeable about and committed to CSHCN increases the likelihood that the plan’s enrollees will have their needs identified and addressed.

Generous and flexible service coverage. In addition to covering a comprehensive array of primary and specialty services, HSCSN delivers and/or supports a range of wraparound services such as case management, transportation, respite, local telephone, and mentoring services. Due to the limited resources of related public service delivery systems that also serve their enrollees, the plan routinely assumes responsibility for arranging and paying for mental health, early intervention, and special education services that could arguably be the responsibility of other public service delivery systems. Nonetheless, the plan’s willingness and ability to pay for this extensive array of services has afforded its clients the benefits of being served in a coordinated fashion within one comprehensive system.

Easy and effective referral arrangements. In addition to facilitating clients’ access to care in the manner discussed above, the plan also permits children’s plans of care to serve as prior authorization for all services outlined in these care plans. In this way, HSCSN has removed the burden on families common in managed care systems of obtaining multiple prior authorizations for anticipated specialty services. Each of these features responds to the special needs of chronically ill and disabled children and their families and, together, helps to create a system of care uniquely suited to this special population.
B. Financing

To a significant degree, the ability of any managed care plan to provide a comprehensive and coordinated service delivery approach depends on the solidity of its financing. Key informants identified several factors that can be credited with significantly contributing to the plan’s early apparent success, including its employment of an intensive case management model to support enrollees and their families, fair payment rates to participating providers, and generous coverage of a broad array of medical and wrap-around services. The plan’s ability to support these policies reflect two key features of the plan’s financing arrangement with the District’s Medicaid agency:

- **Adequacy of payment rate.** The early experience of HSCSN suggests that the capitated rate the plan receives from Medicaid has been adequate and provides the appropriate incentives to render high quality care in a flexible and coordinated manner. The adequacy of this rate is also probably a reflection of the likelihood that HSCSN experienced favorable selection, at least during its first year or so, among SSI-enrolled children in the District. As mentioned above, cost settlement at the end of the waiver’s first year resulted in HSCSN having to repay the District profits in excess of those permitted under its risk-sharing arrangement. Whether this beneficial payment arrangement will continue in years to come will depend on the evolving case mix of enrollees in the plan; should the waiver institute mandatory enrollment of all children on SSI, for example, the program could expect to see higher base costs. Growing costs of serving CSHCN have already begun to affect the service delivery model; key informants recently indicated that the plan has had to lay off some of its case management staff to reduce administrative costs, and previously-satisfied parents have already begun reporting increased problems in accessing services and equipment for their children.

- **Capitated reimbursement.** The second critical factor in the plan’s ability to support its comprehensive system of care is the fact that the plan is paid through a capitated arrangement. This capitated approach enhances the plan’s freedom to use funds creatively by exempting the plan from often-restrictive definitions of allowable services imposed on the Medicaid agency—flexibility which plan officials note often saves money. For example, HSCSN is able to use its capitated payments to cover phone service for enrollees, a benefit that the Medicaid agency would not be able to cover under its traditional fee-for-service system.
During the demonstration period, Medicaid paid HSCSN the same capitation rate—approximately $1000 per member-per month—for all enrollees. Based on the cost experience gained over the course of the demonstration, however, Medicaid is considering developing two to three risk adjusted rates for when the contract is rebid.

C. Identification and Enrollment

As discussed above, the District’s Medicaid managed care model for CSHCN is targeted to children who are eligible for SSI. Given the complexity of operationalizing a broader definition of CSHCN, targeting the program to this easily identifiable population was an administratively feasible approach. In limiting the program to SSI eligibles, however, the District made the trade-off that many CSHCN, such as those with HIV or diabetes, would remain in the traditional fee-for-service system or in a mainstream managed care plan. However, building on the positive experience of the demonstration program over the past several years, Medicaid officials are now considering expanding eligibility for the program to foster care children. This move would help to extend the benefits of the waiver program to a population with considerable health and other related needs while maintaining the administrative simplicity of the current eligibility approach.

Although the waiver program to date has been limited to the pool of easily identifiable SSI-enrolled children, the District has nonetheless experienced significant difficulty in reaching the target population due to such problems as families not returning the enrollment card mailed by the Medicaid agency, providers discouraging enrollment by their patients, and the difficulties of locating many families with children on the SSI rolls. Given these factors, outreach has played a critical role in facilitating client enrollment. As described earlier, the HSCSN plan conducted extensive in-person outreach to SSI eligibles who did not respond to the enrollment package mailed by the Medicaid agency, and continues to do so as needed. That plan representatives rather than neutral enrollment brokers conduct this outreach is a potential concern, as one parent described feeling like “there was no choice” about whether or not to enroll when visited by the plan representative. However, the HSCSN plan’s tailored approach to special needs
children as compared to that of mainstream managed care systems, along with consistently positive reports (including by the aforementioned parent) of the plan’s excellent performance, minimizes the potentially negative implications of a direct marketing situation of this nature. Had the plan been a for-profit entity, or if this non-profit plan had not been subject to repay significant profits to the District, more concern about this approach might be warranted.

In addition to this type of outreach, further education of families with children already on SSI but remaining in the fee-for-service system, as well as better identification of children eligible for but not yet enrolled in SSI, could be facilitated by improved education of hotline staff who handle Medicaid managed care inquiries. Key informants report that these staff tend to have little knowledge of the needs of and resources available to CSHCN, including the waiver program and, therefore, miss opportunities to link eligible children to Medicaid’s special network for disabled children on SSI.

D. Family Involvement in System Planning, Implementation, and Oversight

The District’s managed care system for SSI children offers important examples of ways in which families can be actively involved in the design and oversight of managed care systems. Ways in which the District Medicaid agency and the HSCSN plan have utilized family input are highlighted below:

- **Designing the model in response to families’ expressed needs.** According to key informants interviewed for this study, families’ voiced concerns about the problems they were experiencing in getting coordinated care for their chronically ill children provided the impetus for the development of District’s network for SSI children. Families, thus, were clearly at the center of the founders’ efforts to create the unique program. The Medicaid agency also solicited family input into the model’s design which resulted in at least one important policy decision—that to use the care plan as the child’s prior authorization referral to specialists in order to reduce the burden on families for obtaining multiple preauthorization for anticipated specialty services.

- **Involving families in developing and communicating policy decisions.** The Title V program operated by the Office of Maternal and Child Health (OMCH)
The Parent Council was originally established with the District’s Systems Development Initiative grant from the federal Maternal and Child Health Bureau and is now a public-private partnership supported by private funds. Due to the usefulness of the meetings, the Committee is currently considering meeting more frequently, either on a bimonthly or monthly basis. The Committee also currently includes the Medical Director of HSCSN, who also sits on the board of the Hospital for Sick Children Foundation (which includes the Hospital for Sick Children and the HSCSN plan) and, thus, has direct input into high-level decisions affecting both the plan and the hospital.

Health Systems Research, Inc. District of Columbia Page 50

---

11 The Parent Council was originally established with the District’s Systems Development Initiative grant from the federal Maternal and Child Health Bureau and is now a public-private partnership supported by private funds.

12 Due to the usefulness of the meetings, the Committee is currently considering meeting more frequently, either on a bimonthly or monthly basis.

13 The Committee also currently includes the Medical Director of HSCSN, who also sits on the board of the Hospital for Sick Children Foundation (which includes the Hospital for Sick Children and the HSCSN plan) and, thus, has direct input into high-level decisions affecting both the plan and the hospital.
E. Executive-Level Interagency Coordination

As discussed throughout this chapter, HSCSN is by all reports doing an admirable job of coordinating a broad range of services for enrolled children, in large part because the plan has tended to assume primary responsibility for ensuring that all needed services are provided and paid for. However, the plan essentially operates in isolation, disconnected from many of the public systems in the District that serve similarly needy children. As discussed above, this situation is reflective of the historical and ongoing lack of coordination between the District’s executive-level agencies. For example, the Medicaid agency reported significant challenges in collaborating with other agencies to develop the waiver program and, therefore, developed the program with little input from other agencies. (Other officials, however, reported that the Medicaid agency could have been more open to the involvement of other agencies, including Title V, in the waiver development process.) However, Medicaid officials acknowledge that, as the payer for services, the Medicaid agency perhaps remains in the best position to facilitate collaboration among agencies serving the same populations and has continued to work over the course of the demonstration to “sell” the program to other agencies.

Not surprisingly, this lack of coordination at the policy level has spilled over into practices at the service delivery level. While on paper the HSCSN plan is required by Medicaid to coordinate with other agencies, the plan has not established any formal agreements with other agencies serving special needs children regarding service coordination. Only due to informal one-on-one arrangements between case managers, teachers, and other front-line workers, other public systems’ tendency to refer eligible children to the HSCSN for services, and the plan’s payment for and coordination of an extensive array of needed services has the plan been able to provide coordinated services for its clients. However, significant opportunity for improvements exist. Even short of formal interagency agreements, improved coordination between the plan and other agencies could be attained, for example, by the institution of ongoing standing interagency meetings to address cross-system issues affecting children enrolled in the HSCSN plan.
IV. Conclusion

The District of Columbia’s demonstration program for SSI children has afforded the country an important opportunity to explore the potential of specialized managed care networks for CSHCN. As discussed in this report, the demonstration program has served to confirm the promise of this approach for meeting the needs of this vulnerable population.

In particular, the experience illustrates that a specialized managed care network offers the opportunity to create a more appropriate and responsive system of care for CSHCN and their families than that offered by mainstream managed care. Among the most important strengths of the District’s specialized network identified by this study are its intensive system of case management; its vast network of traditional and nontraditional medical, mental health, and support providers; and a comprehensive and flexible service package including an array of benefits not typically covered by mainstream managed care plans. The plan’s utilization of the child’s care plan as preauthorization for specialty services is another important and unique feature of HSCSN’s approach to facilitating enrollees’ access to needed services.

The District’s experience also highlights the importance of financial arrangements to the success of the specialized managed care network. The District’s generous capitated payment to the HSCSN plan and, in turn, the plan’s generous and timely reimbursement of providers were critical factors in facilitating the plan’s broad enrollment of providers and flexible service coverage policies. The plan’s status as a non-profit entity is also likely to have facilitated its acceptance by the provider and consumer communities, while risk corridors minimized concern of how profits or losses incurred by the plan might affect its practices.

While specialized managed care networks offer a positive and promising development for Medicaid-eligible CSHCN who are eligible for them, it is important to be aware of how parallel
systems of care for CSHCN who are not eligible for these special systems are working. In the District, because the special network for CSHCN is limited to children on SSI, many CSHCN are enrolled in the mainstream managed care system where relatively little attention has been paid to enhancing mainstream managed care plans’ responsiveness to the special needs of CSHCN and their families. Therefore, in the District, as in other states pursuing specialized managed care networks for CSHCN, attention to how to best serve CSHCN in parallel mainstream managed care systems remains a critical counterpart effort.
Appendix A: Key Informant List
Appendix A: Key Informant List

The following persons were interviewed by researchers of the National Policy Center for Children with Special Health Care Needs in their study of the District of Columbia’s specialized managed care network for CSHCN:

Medical Assistance Administration
  Ellie Tinto
  Maude Holt
  Deborah Jones

Health Services for Children with Special Needs, Inc.
  Mary Tierney
  Rod Hodge

Office of Maternal and Child Health, Department of Health
  Joni Eisenberg
  Joyce Brooks
  Barbara Hatcher (former Director OMCH)

Commission on Mental Health Services
  Juan Lovelace
  Nick Geleta

Commission on Social Services, Part C Program
  Tammy Procter

Child and Family Services Agency, Foster Care Program
  Eleanor Everett

DC General Hospital
  Jacqueline McMorris, Special Needs Clinic
  Parent Advisory Council Members
Case Study: Florida

I. Background and Introduction

Like many other states across the country, the State of Florida began experimenting many years ago with managed care as a strategy for improving access to and quality of care for its low-income citizens, and over the last 20 years, the state’s utilization of managed care has continued to grow. For an even longer period of time, the state has relied on its Title V/Children’s Medical Services (CMS) program to serve the state’s chronically ill children. As many children served through CMS are Medicaid eligible, Medicaid has historically paid for many services rendered by CMS providers. However, in 1996, drawing upon its experience in the managed care arena, the state decided that CMS could better serve its Medicaid-eligible enrollees through a managed system of care. Toward this end, the legislature directed CMS to establish a Primary Care Case Management (PCCM) program to serve Medicaid-eligible children with special health care needs. This case study reports on Florida's experience in operating this specialized PCCM program.

A. Medicaid Managed Care and CSHCN

The development of Florida’s Medicaid managed care system began in the early 1980s with the implementation of capitated Health Maintenance Organizations (HMOs) in which Medicaid recipients, including those eligible through the SSI program, have been able to participate on a
In its efforts to continually improve and refine its Medicaid managed care systems for CSHCN, in the mid-1980s the state began considering options for formally integrating its managed care systems with the state’s strong Title V/CMS program. The legislature determined that CMS should function as a managed fee-for-service program—a PCCM arrangement—for Medicaid-eligible CSHCN. Specifically, the Senate Bill 866 legislation passed in June 1996 designated CMS as a specialized MediPass arrangement and was initially named the Alternative Service Network. It is more recently referred to as the “CMS Network.” With this move, Florida built on the strong track record of the state’s Title V/CMS program by making the CMS Network the centerpiece of the state’s managed care system for CSHCN.\footnote{In accordance with a later decision of the state legislature, the CMS Network will become a full risk-bearing entity as of July 1999. The CMS Network’s three years of experience as a PCCM model served as a critical transition phase which allowed the CMS program to later become a fully capitated entity at risk for services to Medicaid-eligible CSHCN. However, at the time of this writing and for the purposes of this study, we examined its structure as a specialized PCCM model.} The following section discusses the state’s CMS program and the characteristics that qualified it for this critical role.

B. Florida’s Title V/CMS Program
Florida’s Children’s Medical Services Program (CMS), administered by the State’s Department of Health, has long been the cornerstone of the state’s system of care for CSHCN, including those with and without eligibility for the state’s Medicaid program. Eligibility criteria for CMS are very broad. CMS-eligible children include those under age 21 who meet financial eligibility criteria and whose serious or chronic physical or developmental conditions require extensive preventive and maintenance care beyond that required by typically healthy children. Children who have one of a long list of identified chronic medical conditions are eligible for CMS, as are children who are eligible for the state’s Part C/Early Intervention program or who are abused or neglected. Children diagnosed with mental health problems who do not have a physical disability are not eligible for CMS.16

The CMS system offers a comprehensive continuum of services including prevention and early intervention services, primary care and specialty care services, as well as long-term care services for medically-complex, fragile children. These services are delivered through a network of private-sector community-based, multidisciplinary, regional and tertiary pediatric providers with demonstrated expertise in the care of CSHCN. The CMS program administers a rigorous credentialing program that reviews providers’ experience and expertise with CSHCN; those passing CMS criteria are added to the CMS network.

At the local level, CMS is administered through 22 regional offices (known as “area offices”) distributed across the state. These CMS offices play a central role both in managing local CMS provider networks as well as arranging for and providing needed services to enrolled families. Staff in the area offices are responsible for determining program eligibility; enrolling eligible children; identifying, recruiting, and credentialing CMS physicians; managing and staffing specialty clinics; and handling client grievances. Perhaps most importantly, local CMS office staff provide intensive case management support, a core CMS service, to enrolled families.

---

16 As discussed in more detail later, Florida’s Title XXI State Children’s Health Insurance Program (CHIP) allows a limited number of children with serious emotional disturbance to enroll in the CMS Network, with behavioral health services provided by the CMS program.
C. Structure and Approach to State Site Visits

The information presented in this case study is based on interviews that researchers from the National Policy Center for Children with Special Health Care Needs conducted during the latter half of 1998. Specifically, the researchers interviewed a range of state and local officials, public and private providers, and parents through both telephone and in-person interviews, as follows:

- In the summer of 1998, researchers conducted structured telephone interviews with state Medicaid and Title V/CMS officials to discuss the evolution of the state’s Medicaid managed care systems and the development, implementation, and operational experiences of Florida’s CMS Network. These interviews set the stage for and helped to structure a follow-up site visit to obtain additional information about the CMS Network and related systems.

- In October 1998, the same researchers conducted a three-day site visit to Florida’s capital, Tallahassee, as well as Tampa, a city rich in resources for children’s specialty care. A combination of individual and group interviews were conducted during this site visit with state Medicaid, Mental Health, Developmental Disabilities, and Department of Education officials; parents of children with special health care needs; the directors of two local area CMS offices; officials and providers of a local early intervention program; a managed care consultant; and administrators of the Healthy Kids Program, one of the state’s health insurance programs for uninsured children. In addition, a follow-up telephone interview was conducted with a representative of Tampa’s children’s hospital who was unavailable during the site visit. (A list of key informants is included in Appendix A.) Each of the interviews was guided by one of several structured protocols targeted to the particular orientations of the interviewee.

D. Organization of Report

The remainder of this report is divided into two sections:

- Section II provides a detailed summary of the structure and operation of Florida’s CMS Network for CSHCN, including a discussion of eligibility, identification, and enrollment; primary care; specialty care; case management; and links to other important systems of care for CSHCN, including the early
Section III discusses lessons learned from the CMS Network experience regarding the development and operation of integrated Medicaid managed care systems for CSHCN. In particular, lessons related to state-level interagency coordination, family involvement, identification of CSHCN, service coordination, financing, and quality assurance are addressed.

II. The Model

In contrast to most of the other states analyzed in this study, Florida’s Medicaid managed care system for CSHCN is distinguished by the central role of the state’s Title V/CMS system and its utilization of a Primary Care Case Management managed care model. This section details information regarding the structure and operation of this unique model.

A. Overview of Model

The CMS Network is a comprehensive system of managed care built upon the state’s Title V/CMS system. The CMS Network represents a merging of both the Medicaid and CMS programs designed specifically for, and including only, Medicaid-eligible children with special health care needs. Children eligible for the CMS Network must receive their care from a network of primary care and specialty physicians and other hospital-based providers credentialed by and included within the state’s Title V/CMS system. CMS-eligible children receive case management services from local area CMS nurses. In accordance with its structure as a Primary Care Case Management arrangement, all enrolled children are linked with a primary care provider who is responsible for providing all preventive and primary care services, as well as managing referrals for specialty and ancillary care. In return, these physicians are reimbursed on a fee-for-service basis for the care they render and paid a monthly administrative fee of $3 per member per month for care management. Specialty providers are likewise reimbursed on a fee-for-service basis for the care they provide. Thus, neither the CMS program
nor its network providers are at financial risk for the high cost of caring for CSHCN enrolled in the program.

While the CMS Network covers a broad array of medical services, certain important services likely to be needed by many special needs children must be obtained outside of the CMS Network. These include mental health, early intervention, special education, and other services delivered through separate public systems. These systems directly bill Medicaid for covered services and receive reimbursement on a fee-for-service basis. Although these services are “carved out” of the explicit responsibility of the CMS Network, CMS case managers work to ensure that their clients are well linked with these systems of care and that services are delivered in a coordinated manner. This coordinated approach, along with the CMS process for credentialing providers and providing ongoing quality monitoring, ensures that the CMS Network functions as a managed health care system, not simply as a traditional fee-for-service reimbursement system.

B. Eligibility, Identification, and Enrollment

Identification of children for the CMS Network is facilitated by outreach efforts of the CMS program. For example, CMS local staff routinely attend tertiary care centers with neonatal intensive care units to identify infants with CMS-eligible conditions and help enroll them in the program. In addition to identifying clients through hospitals, the program also encourages and receives referrals of potentially-eligible children from physicians, parents, and other programs serving CSHCN, such as Part C. Once a potential client is determined to be eligible for CMS, a Medicaid eligibility determination is also performed, if necessary. If the child is already a Medicaid recipient, the CMS worker counsels the family about their option to enroll the child in the CMS Network.

Accessing the CMS Network can be more problematic for children who first enter the system through Medicaid, however. The routine Medicaid enrollment process involves a step during which families are asked to choose among the managed care options available to them, namely
either an HMO or a MediPass provider. Persons not exercising their choice are assigned to an HMO or PCCM provider in their area.\textsuperscript{17} Medicaid enrollment broker staff do not routinely inquire about children’s special health care needs that might qualify them for the CMS Network; in fact, the CMS Network is not even presented as an option to new recipients. Thus, families with CSHCN who are not already aware of CMS are likely to end up in either MediPass or a mainstream Medicaid HMO. If these families subsequently learn of their eligibility for the CMS Network, they must disenroll their child from the HMO or PCCM before they can re-enroll in CMS. However, reports from key informants that HMOs have little knowledge or understanding of the state’s public resources or systems of care for CSHCN suggests that, despite the financial incentive to them to do so, HMOs are not likely to link eligible children within their plans to the CMS Network. These factors may have led to some of Florida’s Medicaid-eligible CSHCN being served through the mainstream managed care system rather than the specialized managed care network operated by CMS.\textsuperscript{18}

C. Primary Care

For children with serious health problems, the need for ongoing specialized medical treatment may overshadow the need for regular primary care. However, as is the case for all children, primary care represents an important component of comprehensive health care for CSHCN. Florida’s CMS program has included primary care as an essential part of its service continuum for CSHCN since the early 1980s and has strived to link program enrollees with a medical

\textsuperscript{17}Florida has historically experienced very high rates of auto assignment, sometimes as high as 80 percent. Up until recently, persons were assigned to HMOs and MediPass providers in the same proportion as enrollees who chose to enroll in each of these systems. This policy worked to the disadvantage of HMOs, as most recipients who choose providers have tended to choose the MediPass program. However, in response to lobbying by HMOs, the policy was recently changed to require that an equal balance between Medicaid recipients in HMOs and PCCMs be established and maintained, the effect of which will be to increase the number of recipients, including CSHCN, who will be assigned to HMOs.

\textsuperscript{18}Since the time that key informant interviews were conducted for this study, Medicaid has significantly reduced the likelihood that CSHCN will be enrolled in mainstream HMOs with improvements in its enrollment procedure. In late 1998, the state revised the script used by its enrollment broker (Benova) to include a query about any special health care needs of child enrollees and, as appropriate, discuss the CMS Network as an enrollment option.
home. This stress on providing the comprehensive continuum of services to CSHCN positioned Florida’s CMS program to become the state’s comprehensive managed care model for chronically ill children.

The program’s ongoing efforts to link Medicaid-eligible children to primary care physicians, however, have been frustrated by the paucity of available pediatricians. According to program officials and parents interviewed for this study, this situation can largely be attributed to Medicaid’s historically low reimbursement rates, which discourage provider participation, as well as to general provider shortages in certain areas of the state. The limited supply of primary care providers has made the already difficult task of finding a pediatrician who understands their child’s needs that much harder for parents. Even in cases when they are able to locate a provider in their community, parents report that it often seems like physicians do not spend sufficient time with them or that they discourage office visits altogether. This behavior is attributed to both the low rates paid by Medicaid, as well as to productivity pressures applied by managed care organizations, which create disincentives to serving children with complex conditions in a primary care setting.

With the development of its Network, CMS undertook a significant effort to improve its capacity to link clients with locally-based primary care providers who are qualified in the special health care needs of chronically ill children. The Network’s creation also marked the initiation of the CMS program’s reimbursement to primary care providers for routine well-child care delivered to program enrollees. Starting in 1996, each local CMS office was required to develop a plan for recruiting, credentialing, and enrolling local primary care providers with expertise in serving CSHCN into its area CMS Network as MediPass providers. CMS

---

19 In response to this problem, the 1999 Florida legislature authorized a pediatric fee increase.

20 To be a primary care provider in the CMS Network (a “CMS Consultant”), the provider must meet the following credentialing criteria: (1) be board certified in pediatrics or family medicine; and (2) have hospital privileges at a designated CMS facility, or have arrangements to place patients in a designated CMS facility through a CMS Consultant. CMS grants waivers of these criteria in locations where there is very little provider capacity and for providers who are waiting to receive their board certification.

21 As noted earlier, the CMS Network is a component of the state’s broader MediPass PCCM program.
officials report that although Medicaid’s low payment rates continue to represent a barrier to recruitment, providers’ response has been quite positive, due in large part to the case management support that is provided by the CMS program. CMS officials report that the program’s recruitment efforts have succeeded in increasing the base of providers available to serve Medicaid-eligible CSHCN.

CMS Network primary care providers are expected to provide preventive and primary care services to CMS clients in accordance with the rules of Medicaid’s Child Health Check-Up program, formerly known as the Early and Periodic, Screening, Diagnosis, and Treatment (EPSDT) program, and CMS case managers play an active role in ensuring that clients receive routine well-child care. In addition, the program now makes immunizations available to CMS clients at certain specialty clinics. These developments have further strengthened the CMS system’s capacity to deliver, in an integrated manner, the comprehensive range of services needed by CSHCN.

D. Specialty Care

Children eligible for Florida’s Medicaid program, with its inherent Child Health Check-Up rules requiring coverage of all medically necessary services, have access to a broader set of benefits than most children covered by private insurance. This is due in large part to the state’s implementation of significant Medicaid coverage expansions of treatment services in response to the federal Omnibus Budget Reconciliation Act of 1989 (OBRA-89) legislation. However, in contrast to CSHCN on Medicaid who receive care through mainstream HMOs or the regular MediPass program, children enrolled in Florida’s CMS Network have access to an especially rich benefit package geared to the special needs of chronically ill and disabled children and their families. This may be credited to several special features of the CMS Network, specifically:

- CMS Network enrollees must receive prior authorization from their primary care providers for specialty services, just like other managed care participants. However, primary care providers in the CMS Network are specially credentialed
to serve CSHCN and are, therefore, more likely to understand their needs and provide referrals more readily.

- To minimize the need for multiple referrals for the various equipment, services, and medications often needed by CSHCN, CMS encourages primary care providers to develop time-limited, blanket authorizations to facilitate clients’ receipt of services related to their primary diagnoses.

- Enrollees in the CMS Network have CMS case managers who play an active role in advocating to the Medicaid agency, when necessary, for approval of requested specialty services and equipment.

- Finally, in cases when Medicaid does not approve coverage of a requested service, CMS can draw on general revenue or Title V funds to pay for additional care. Having this revenue source to fund supplementary services outside of those reimbursed by Medicaid is a unique benefit resulting from the Network’s placement in the public agency that serves as the Title V grantee rather than a private managed care organization.

To deliver specialty services to its clients, the CMS program, and therefore the CMS Network, contracts with a statewide network of specialty providers. CMS specialty contracts are concentrated most heavily in university-based tertiary care centers, which operate a range of specialty clinics tailored to the needs of children with particular diagnoses. These clinics are typically staffed by a broad range of hospital-based multidisciplinary providers who provide the range of services needed by these children in one location at the same time, as well as local CMS case managers who provide ongoing care coordination for children served through the clinics. In addition to operating hospital-based clinics, contractors work with local CMS programs to organize and provide satellite clinics for families who live far from major tertiary care centers. In interviews conducted as part of this study, families expressed great appreciation for the satellite clinics, but also the need for more, as many families must routinely travel significant distances to regional specialty care centers so that their children can receive needed care.

E. Case Management
As mentioned earlier, enrollees in the CMS Network receive intensive case management services from locally-based CMS nurses and social workers. Case management is a core service provided by CMS and yet another feature of the Network that contributed to the state’s decision to make the program the centerpiece of its managed care system for Medicaid-eligible CSHCN. CMS case management activities are reimbursed by Medicaid under the targeted case management option as part of the fee-for-service structure.\textsuperscript{22}

Assignment to a case manager is a central component of the CMS enrollment process. State guidance to local CMS offices recommends that clients be assigned to case managers based upon their intensity of need, with case managers with higher intensity clients assigned smaller caseloads than those serving clients with less intensive needs. Toward this end, the state requires CMS staff to use the computerized Family Support Index assessment tool to explore child and family needs and resources in several key domains (environmental, psychosocial, health, and physiological) and indicate the level and intensity of case management appropriate for each client. Another tool designed by the state—the Family Support Assessment—is used as a counterpart to the Family Support Index by guiding the case manager in soliciting information from the family relevant to determining the appropriate intensity level of case management.

While all local CMS offices utilize this tool, our study found that the local programs actually vary in the way they assign case managers to clients. Some programs we spoke with assign children based on their condition type—an approach that ensures that families are linked with case managers who have special expertise regarding their children’s particular needs. Others assign case managers based on the geographic regions in which families live; since much of the case management provided occurs in clients’ homes, this design is intended to improve overall efficiency and productivity. Typically, a combination of these factors come into play in making case manager assignments. All CMS offices, however, have a case manager designated to

\textsuperscript{22}It has not yet been determined whether case management will continue to be reimbursed through a fee-for-service arrangement when the CMS Network becomes an at-risk agency or whether case management will be folded into the capitation rate along with other services.
coordinate the care of children who are dually eligible for the state’s Part C/Early Intervention program and CMS (as will be described further below).

Despite variable practices with regard to assigning case managers to clients, CMS nurses and social workers tend to engage in a very consistent set of activities across the state. These activities include linking clients to primary care providers; monitoring the receipt of well-child services; coordinating referrals for specialty care and equipment; scheduling appointments; arranging for transportation assistance; facilitating information exchange among clients’ different providers (particularly by ensuring that specialty provider reports are sent to primary care providers); and linking families to other systems of care to access needed resources. At its core, CMS case management aims to ensure that families have access to all the resources they need, including not only health services but also any and all related support to assist them in coping with their child’s condition and optimizing the family’s functioning.

Case management services provided by staff are supplemented by peer support provided by resource parents, who are paid staff of the CMS program. Resource parents are parents of participating children who agree to provide peer support to other families dealing with similar challenges of raising a child with serious health problems and to assist them in accessing needed resources.

The CMS case management approach was noted by key informants, including parents, as being very different from that provided by HMOs. Whereas CMS’ focus is on facilitating access to services and linking with community resources, HMOs were noted as focusing more on utilization management and cost containment. Parents interviewed for this study rated the case management provided by CMS very positively. However, even acknowledging the assistance provided by CMS, parents still tended to identify themselves as having primary responsibility for managing their children’s care.

F. Links to Other Systems
Although the CMS Network covers an extensive array of medical and support services, CSHCN often require services from one or more additional separate systems of care, depending on their particular needs. This section discusses several of these systems in Florida and their relationship to the CMS Network.

1. Early Intervention

For infants and toddlers with, or at risk of, developmental delays, the Part C/Early Intervention program offers an important array of services to promote appropriate development. Florida’s Part C program serves children from birth to 36 months of age who have a genetic or metabolic disorder, neurological abnormalities or insults, severe attachment disorder, significant sensory impairment, or demonstrate developmental delay. Many of these children are also eligible for the state’s CMS program. In fact, CMS is the lead agency for Part C—an administrative role that has certainly facilitated integration between the two programs.

Referrals for Part C commonly come from parents, physicians, and hospitals. Given the overlap in their populations, CMS nurse liaisons to hospital neonatal intensive care units often identify children who are eligible for Part C as well as CMS. When a child is identified as being potentially eligible for Part C, a developmental evaluation is conducted. If that evaluation confirms eligibility for the program, an Individualized Family Service Plan (IFSP) is developed.

Florida’s Part C program contracts with a network of 16 private-sector early intervention contractors, many of which are university-based, to serve the state’s 67 counties. These regional centers, which are staffed by multidisciplinary teams of professionals including physicians, psychologists, nurses, and social workers, provide a set of “core services” to the target population. These core services include identification, eligibility screening, evaluation, care coordination, service authorization, and development of IFSPs. To avoid conflicts of interest, these centers are not permitted to directly provide the therapies or other service interventions for which they evaluate need. Instead, referrals are made to community-based providers for recommended care, most often physical, occupational, and speech therapy, and equipment such as sensory aids, assistive communication devices, and developmental toys.
State-level integration between the Part C and CMS programs has fostered the development of policies and structures to facilitate coordination at the service delivery level between these two programs. For example:

- All children eligible for Part C are also eligible for CMS (as long as they meet CMS financial eligibility criteria); therefore, Part C eligibles who are also Medicaid eligible may enroll in the CMS Network.

- As indicated above, efforts to identify eligible children are coordinated through the work of CMS nurses stationed in NICUs who identify children potentially eligible for both Part C and CMS.

- Evaluations conducted by CMS and Part C are each recognized and accepted by the other, and plans of care for dually-eligible children are developed through a coordinated effort of the staff of the two programs.

- To facilitate the coordination of services provided to dually-eligible children, each local CMS program has a designated case manager, funded by Part C, to manage the caseload of CMS children who are on Part C and also to serve as the liaison between the two programs. This person is the child’s primary service coordinator and, as such, is instrumental in developing the child’s IFSP.

- Early intervention services for Medicaid-eligible children in the CMS Network must be authorized by the child’s primary care provider, the same person who must authorize specialty services delivered by CMS providers, thus further promoting coordination of services for children receiving care from multiple providers.

- Local Part C and CMS programs in different parts of the state, along with other local agencies and providers serving maternal and child populations, have entered into formal Memoranda of Understanding to improve the coordination of care across the different organizations.

The state’s efforts to coordinate the Part C and CMS programs have not gone unnoticed by parents who, in interviews with researchers, rated coordination with Part C as a particularly strong feature of the CMS program.

Collaboration between Medicaid and Part C officials has also been important to the program, particularly with respect to the development of locally-assigned special billing codes for early intervention services.
2. Special Education

Another service that many children in the CMS Network are likely to need is special education. In accordance with federal law, Florida’s 2,500 schools are required to ensure that all children have access to a free, appropriate, public education regardless of disability. In keeping with this law, schools operate special education programs to provide children with disabilities that affect their ability to learn with the services they need to support their educational development.

Special education services include evaluation of children to determine their eligibility for services; the development of an Individual Education Plan (IEP) for children determined eligible that outlines the services that are to be provided; and the services themselves, which typically include physical, occupational, and speech therapy, as well as nursing and social work services. Arrangements for providing health services vary by school and/or school system; some schools have professional caregivers on site, while some contract for services to be delivered by community providers. Tampa has a unique arrangement whereby the local school system and children’s hospital share therapists, an arrangement established in the early 1990s in response to two factors: schools’ problems in hiring and retaining skilled therapists, and the desire to improve the continuity and quality of care for children who have received early intervention services from the hospital and are now transitioning out of early intervention and into the special education system.

Children in the CMS Network do not need approval by their primary care providers to receive special education; these services are reimbursed separately by the Medicaid program. However, given the central role that schools play in children’s lives and the need to coordinate services provided by different therapists and other providers in different settings, CMS case managers routinely contact schools regarding the delivery of special education services and many participate in the development and monitoring of their clients’ IEPs. In recognition of the fact that schools could play a more proactive role in sharing information with medical providers regarding services provided in schools, the state Department of Education has developed a draft Memorandum of Understanding as a model for the type of agreements that schools and local
HMOs could enter into to facilitate information sharing. At the time of this writing, however, no such memoranda had been negotiated.

Parents interviewed for the study indicated that, in contrast to the comprehensive level of services they receive through the early intervention program, access to special education services is far more restricted. This, they believed, is due to several factors, including special education’s often narrow interpretation of what conditions impact a child’s ability to learn. Furthermore, investigators heard numerous reports of schools’ severe overcrowding and general lack of resources, conditions which limit schools’ capacity to provide the services and support that disabled children need.

Interestingly, Medicaid has become the focus of a recent new initiative to enhance the funding base for schools, as well as communities more broadly. The state is involved in a major Medicaid administrative claiming effort to facilitate schools’ ability to draw down Medicaid dollars for outreach and service delivery to Medicaid-eligible children. The state Department of Education has urged schools to direct a portion of reclaimed monies to support special education enhancements and other classroom activities that are drawing down federal Medicaid funds. Individual school districts and local governing boards, however, have thus far tended to favor using these monies for other purposes.

C. Mental Health

As indicated earlier in this chapter, children affected by mental health conditions without an accompanying physical condition that meets the criteria for CMS eligibility may not enroll in the CMS Network. However, children with physical disabilities commonly are dually diagnosed with mental health and/or behavioral disorders and, thus, require the services of mental health professionals. State officials report that, during fiscal year 1995-1996, 7 percent of the CMS population had a mental health diagnosis, a figure which CMS officials note is likely an underestimate of the true prevalence of mental health problems among program enrollees. CSHCN also often need basic counseling, behavioral programming, and emotional guidance to help them cope with their physical conditions, and the parents and families of CSHCN often
need counseling to help them cope with the tremendous amount of stress related to the impact of having a child with special needs in the family. However, mental health services are not included in the scope of benefits covered by the CMS Network. Therefore, participants must go outside of the CMS system to receive this care.

According to key informants interviewed for this study, Medicaid recipients’ access to private mental health providers is severely limited. This was attributed to a general paucity of mental health providers, as well as two particular reimbursement-related issues:

- First, although Medicaid will reimburse psychiatrists in private practice, current program policy only permits reimbursement of the limited number of private psychologists and family therapists who participate in the public mental health system as contractors with Community Mental Health Centers. Thus, only a small portion of the mental health providers in private practice in the state are eligible for Medicaid reimbursement.

- Second, even if they are eligible for Medicaid payments, many providers are unwilling to participate in Medicaid due to the program’s low reimbursement rates.

Given their limited direct access to private mental health providers, Medicaid-eligible children must often rely on the public mental health system which is under the administration of the state’s Department of Children and Family Services. The program targets three priority groups of children under age 18—those with serious emotional disturbance, emotional disturbance, or who are at risk of emotional disturbance. Although financial criteria have not historically been imposed for children’s services, services are now being targeted to low-income children. Services are delivered by the approximately 300 providers contracted by Children’s Mental Health, including Community Mental Health Centers, independent providers including psychiatrists and psychologists, and residential programs. However, Florida’s Community Mental Health Centers were described as sometimes being structured to better serve adults than children.

Despite the high level of need for mental health services among CMS clients, both CMS and Children’s Mental Health officials reported that links between the two systems, at both the state
and community levels, are weak. For example, in contrast to CMS’s relationships with Early Intervention and Special Education, no formal structures exist between CMS and Mental Health to link the two systems and facilitate information exchange among providers. Key informants noted the potentially serious outcomes that can result from this lack of coordination, including complications resulting from poorly coordinated medications being prescribed by different providers in the medical and mental health systems. However, under the state’s new Title XXI initiative, the state is taking important steps to improve coordination of mental and physical health care for CSHCN, as will be discussed in below.

4. Developmental Services

Another resource for CSHCN in Florida is the state’s Developmental Services (DS) program. DS serves approximately 8,000 developmentally disabled children living in the community, including children eligible for the state’s Medicaid home and community-based waiver program. Children eligible for DS include those with such conditions as mental retardation, autism, cerebral palsy, spina bifida, and children at high risk for developmental disabilities. Before the implementation of the Part C/Early Intervention program, DS provided services to children from birth; however, services for the birth-to-three population were moved under the Part C program when that program began, and DS now serves children beginning at age three and through adulthood. Services and supplies often paid for by DS include communication devices, massage and other therapies, respite care, companion services, diapers, wheelchairs, and home modifications, among other services that many children on CMS often need.

DS officials report that most referrals into their program come from schools, parents and parent groups, welfare eligibility workers, and the health department, as well as CMS. In fact, officials reported that children in CMS were far more likely to be linked to DS services than CSHCN in HMOs. However, interviews with parents suggest that traditionally strong ties between the DS and CMS programs have weakened since Part C assumed responsibility for the birth-to-three population. Parents report that, since that shift, they are less likely to be told about and linked to DS. Both program officials and parents agree, however, that DS offers a flexible source of funds for gap-filling services needed to keep children living in the community (either at home or
in residential programs) that are not covered by Medicaid, and that coordination between DS and CMS is important.

III. Directions for the Future and Lessons Learned Regarding Service Integration

Building on the CMS Network’s three years of experience functioning as a PCCM model of care, the state is now in the process of transitioning the CMS Network to a capitated program. Driven by the opportunities provided by the federal Title XXI State Children’s Health Insurance Program (CHIP) legislation to create more inclusive systems of care for children, namely by providing insurance to previously uninsured children, Florida is creating an integrated system for identifying and serving children eligible for Medicaid and CHIP. Within this system, the CMS program in the Department of Health will serve as the Medicaid managed care provider for Medicaid-eligible CSHCN as well as CSHCN funded through Title XXI and, in that role, be at risk for providing services to CSHCN within a set budget.

The decision to capitate the CMS program for the delivery of care to Medicaid-eligible CSHCN was made based upon the program’s experience as a PCCM provider. Through this experience, CMS demonstrated its ability to manage a provider network for CSHCN, and the state developed an invaluable database of claims experience upon which to develop capitated rates for special needs children. As discussed in this section, the experience also afforded the state an opportunity to learn lessons that will benefit CMS as it moves to a capitated system. Those related to state-level interagency coordination, family involvement, systems for identification and enrollment, service coordination, and funding are discussed below.

A. State Level Efforts at Interagency Coordination

Florida has a long history of effective interagency collaboration among its state agencies that, over the years, has spurred the development of many unique initiatives to improve the health of the state’s pregnant women and children. The development and refinement of Florida’s CMS
Network is one of the most recent examples of the benefits that have resulted from Florida’s strong state-level interagency coordination, particularly between the state’s Title V/CMS and Medicaid agencies.

Florida’s Title V/CMS and Medicaid agencies enjoy a uniquely strong partnership, one that has served CMS program beneficiaries well. The close daily working relationships between Title V/CMS and Medicaid officials facilitated the development of a CMS program that initially maximized Medicaid resources during EPSDT coverage expansions following OBRA-89 and later, with the development of the CMS Network, became the centerpiece of the state’s efforts to provide high quality care to Medicaid-eligible CSHCN through managed care arrangements. Recent changes to further develop the CMS Network into a fully capitated program provide further evidence that the strong relationship between the CMS and Medicaid programs will continue to place Florida in the forefront of states working to serve this particularly vulnerable population.

Another strong programmatic relationship that has benefitted children served through the CMS Network is that between CMS and Part C. As indicated earlier, CMS is the lead agency for Part C. This union of the Part C and CMS programs has fostered the development of policies promoting coordination between the two programs, such as that requiring local CMS offices to have one case manager assigned to working with clients dually eligible for CMS and Part C. In addition, because Part C resides within CMS, Part C has, by extension, benefitted from the strong relationship that exists between CMS and Medicaid. For example, when the Part C program was launched in the early 1990s, Part C provided 100 percent funding for a position in Medicaid focused solely on policy and programming issues related to early intervention. After several years, Part C stopped contributing its funding for the position because of decreases in Medicaid reimbursement for early intervention services. The Medicaid agency, however, stepped in to provide 100 percent funding for this state-level position.

Interagency collaboration at the state level has also had the effect of promoting interagency coordination at the local level. For example, local CMS offices have mimicked state office practices by working closely with agencies and providers in their communities and, in some
cases, entering into formal Memoranda of Understanding with other local programs serving high-risk pregnant women and children. In another example of the spill-over effect that state-level collaboration can have, regional Medicaid offices have recently designated individual staff as Part C/CMS liaisons who are charged with addressing interprogram concerns at the local level.

Finally, Florida’s experience illustrates the central role that state legislators can play in promoting interagency coordination. For example, recent demands by the legislature that funding for children’s services be structured in a less categorical way have spurred new working relationships and program coordination that beforehand did not exist. The state’s service delivery developments in response to Title XXI have also spurred and strengthened interagency relationships, such as that between the CMS and Children’s Mental Health programs.

B. Family Involvement in System Planning, Implementation, and Oversight

Florida’s commitment to involving families of CSHCN in program development, implementation, and oversight is evident at both the state and local levels, where parents play an important role in daily program operations. The Title V/CMS program funds two parent consultant positions at the state level to ensure that families have a regular place at the table where policy and programmatic decisions are made about the state’s approach to serving children with special needs. Examples of functions performed by parent consultants include participating in the development of brochures about available programs; developing a parent newsletter; working with parent groups advocating for CSHCN; and helping families understand and use the service delivery system. Parents interviewed for this study emphasized the importance of Florida’s decision to pay parent consultants for these duties, noting that payment helps to place parents on the same level as professionals who are paid to perform similar activities as part of their job responsibilities.
Evidence of CMS’ recognition of the critical role of family involvement is also reflected at the local level. As noted earlier, case management services provided by staff at local CMS offices are supplemented by support provided by resource parents, who work as paid staff to the CMS program to assist families in accessing needed resources and to offer peer support to other families dealing with similar challenges of raising a child with serious health problems.

While acknowledging the state’s support of family involvement in the ways described above, parents also indicated that the state could enhance its effective use of family input by soliciting it earlier in the decision making process rather than after decisions have taken effect. In addition, parents indicated the importance of advocacy training in strengthening parents’ capacity to contribute to decisionmaking processes, training that is currently being provided by the Florida Disability Network.

C. Systems for Identification and Enrollment

Although there are many strengths of the CMS Network, significant room exists for improved efficiency in identifying and linking eligible children to this innovative system of care. As discussed earlier in this chapter, the program has not employed any systematic process for identifying children with special needs who are enrolling in Medicaid to link them at the outset to the CMS Network. Rather, when children are later identified by CMS, they first have to be disenrolled from the HMO or PCCM provider with whom they were initially linked.

Despite this roundabout approach, key informants interviewed for this study consistently indicated that the CMS program, due to its strong presence in the state generally and among the specialist provider community specifically, as well as its routine outreach efforts in hospital NICUs, does a good job of identifying and enrolling most eligible children into the CMS Network. However, several factors—the state’s high auto assignment rate of Medicaid eligibles, the recent policy change of increasing auto assignments to HMOs, and reports by study interviewees that HMOs have little knowledge or understanding of the state’s public...
resources and systems of care for CSHCN—point to the need for a more systematic approach to identifying CSHCN and enrolling eligible children in the CMS Network.

Progress toward that end, however, is already evident in the state’s approach to linking Medicaid-eligible and uninsured children to its new Title XXI system. First, the application form, which is used to determine eligibility for Medicaid and CHIP and is being distributed through schools and other sites, describes the CMS program for children needing “special care,” a strategy to inform parents about the program’s availability. Second, to facilitate linking children with special needs to the CMS program, the application includes the following question about applicants’ special medical needs: Do any of the children have a medical or developmental condition expected to last more than 12 months? All applications with positive responses to this question are forwarded to CMS for eligibility determination. All children found to be eligible are directed to the CMS program and, if they are Medicaid eligible, to the CMS Network. As the state gains experience in this more systematic approach to identifying, screening, and enrolling children in the CMS Network through the Title XXI system, perhaps modifications will be made to more expeditiously link CSHCN accessing Medicaid through traditional routes to the CMS Network.

D. Systems for Service Coordination

A clear benefit of enrollment in the CMS Network is the receipt of case management services from a CMS nurse or social worker. The variety of activities performed by CMS case managers help to facilitate the delivery and integration of the range of services needed by chronically ill children and their families. In contrast to children in the CMS Network, children in the mainstream managed care system are not routinely provided with this type of coordination, support, and advocacy. Rather than facilitating access to and coordinating a range of services, case management provided by HMOs is typically aimed at containing costs.

23 In addition to being distributed through schools, applications are provided in county health departments, child care centers, Department of Children and Families service centers, and other locations.
While having a case manager can greatly facilitate access to and coordination of care, having too many case managers working in isolation of one another can be a burden to families, who ultimately end up being their child’s own case manager. As Florida’s mental health, early intervention, and developmental services programs all provide their own case management services, CMS clients who access more than one of these systems of care are likely to be assigned more than one case manager. Thus, coordination among these case managers becomes a key concern. To address this problem, CMS case managers try to coordinate with case managers from other programs who are working with their clients. For example, as discussed earlier, CMS’ designation of a Part C case manager in the lead role for children in both the CMS and Part C programs has facilitated coordination of case management services for these two programs. Policies of the Developmental Services program also require that case managers coordinate with CMS in the development of family care plans for children receiving services from both programs; furthermore, because federal funds cannot be used to pay for two case managers for the same child, coordination must occur to determine who will be the lead case manager.

Another issue mentioned earlier related to service coordination, beyond case management, is the need for improved integration of physical and mental health services. With its Title XXI system redesign, Florida is taking important steps toward better coordinating these services by formally integrating the CMS and Children’s Mental Health programs through two new programs:

- The first is a small program that will initially affect 303 children with serious emotional disturbance. Under this program, Children’s Mental Health funds will flow through CMS; that is, CMS will provide physical services and be capitated to ensure the delivery of mental health services through the public mental health system for this population of children.

- Second, in a move that will affect a larger number of children, Florida’s Title XXI system places responsibility on CMS for an estimated 9,500 children who will be eligible for CMS through Title XXI. Under the plan, CMS will not only be responsible for providing needed physical health services but will also be responsible for addressing their mental health needs (in contrast to the current arrangement whereby mental health needs are carved out of CMS responsibility). Under this arrangement, CMS will have the flexibility under its capitated rate to determine how to best serve its enrolled population. While CMS does not, at
this point, have the same arrangement for the lower-income Medicaid population served through the CMS Network, Medicaid children with physical health problems who also have behavioral problems will fall under the purview of the CMS Network, and CMS will be subject to meeting these children’s needs within its capitated rate.

E. Funding Streams

Two major issues with regard to funding emerged during this study of Florida’s CMS Network. These relate, first, to Medicaid reimbursement rates and, second, to the relationship between funding streams and coordination of agencies serving overlapping populations.

A major issue identified by officials from each of the different systems of care we analyzed in this study was the barrier to provider participation posed by low Medicaid reimbursement rates. Key informants identified low reimbursement rates as a barrier to provider participation generally, and as a particular issue for providers caring for a population with especially intensive needs. Key informants suggested that primary care providers in the CMS Network, who are paid the same $3 monthly case management fee as primary care providers in the broader MediPass Medicaid managed care program, deserve to be paid a higher case management fee to compensate them for the extra care and attention needed by chronically ill and disabled children. Low Medicaid rates, combined with the pressure on managed care providers to see a large number of patients each day, works against providers who are interested in seeing CSHCN and against the children, who require more time from their providers than healthier children.

Another financing-related lesson gleaned from the Florida experience is that integration between programs serving overlapping populations can be improved by merging their funding streams. As discussed earlier in this case study, Florida’s children’s mental health and CMS programs have not traditionally worked together, despite overlap in their target populations; nor have services provided by the two systems been coordinated in any systematic way. However, the state legislature’s recent mandate that children’s mental health service funds flow through CMS has spurred the development of an apparently effective new collaborative working relationship.
between the two agencies aimed at designing more integrated systems of care for special needs children. The institution of this new financial relationship, in turn, has facilitated the development of new service delivery structures to better integrate physical and mental health services.

F. Systems for Quality Assurance, Monitoring, and Oversight

Integral to its role in managing the CMS Network is the CMS program’s responsibilities for quality assurance. As noted by CMS officials, the CMS Network is a system of care designed to address the problems of unmanaged fee-for-service arrangements through the development and management of a well-defined system of care. Unlike a fee-for-service system, for which no one entity takes responsibility, the CMS Network is defined by a state role in shaping and managing the makeup and operation of the system in the following ways:

- Development of comprehensive provider network. The panel of providers that make up the CMS Network include a comprehensive array of primary and specialty care providers who can address the range of needs of CMS clients. Unlike under fee-for-service arrangements, participating providers may only refer to providers in the network, creating a closed system which may be monitored by the state.

- Establishment of provider credentialing criteria. In addition to being a comprehensive network of providers, the CMS Network represents a panel of providers with specific expertise in the care of CSHCN. CMS accomplishes this by establishing provider credentialing criteria which providers must meet to be enrolled in the program.

- Utilization management. In line with its role in providing quality oversight, CMS routinely reviews the practice patterns of enrolled providers and, when necessary, takes steps to manage providers whose practices lie significantly outside normal parameters for their peers.

In line with legislative requirements, CMS also routinely reports on its performance to the state legislature. The program’s performance each year is factored into appropriations decisions for the following year.
A fundamental tool for executing these quality oversight roles is the availability of needed data. CMS officials emphasized the need for strong data systems to provide this needed information but cautioned that their development can take considerable time.

IV. Conclusion

The State of Florida’s experience in operating its CMS Network offers several important lessons regarding the development of Medicaid managed care systems for CSHCN. On a fundamental level, the development and continuing evolution of Florida’s CMS Network illustrates the potentially significant role that state Title V programs can play in the active operation and management of managed care systems for CSHCN. Florida’s history suggests that states best positioned to assume such a role are those with a strong Title V/CSHCN program with a solid track record of providing high-quality services for CSHCN and that, furthermore, enjoys an excellent reputation among providers and consumers. Another critical factor for success is an established and collaborative relationship between the state’s Title V and Medicaid agencies. In addition, strong relationships between Title V and other agencies serving CSHCN both at the state and service delivery level are also important for facilitating an integrated approach to meeting CSHCN’s varied service needs.

On an operational level, Florida’s experience demonstrates the value of implementing a Primary Care Case Management model as an intermediate step toward ultimately developing a capitated Medicaid managed care system. The gradual transition permitted by its use of the PCCM model for several years allowed Florida’s CMS program to make critical enhancements to its existing system, such as its expansion of the primary care provider base, necessary for the success of a program that would later be capitated. In addition, the claims data gathered during the time of the PCCM program’s operation is considered by program officials to be essential to the development of accurate capitated rates for the full-risk model.

Furthermore, Florida’s CMS Network experience illustrates the potential that a specialized managed care network offers for creating a responsive system of care for CSHCN. Florida’s
CMS Network offers features that are designed to meet the special needs of CSHCN and their families and which are not characteristic of the mainstream managed care system. These include its intensive system of case management; strong network of providers with expertise in serving chronically ill and disabled children; and easier access to specialty services due to the use of blanket authorizations; case managers’ advocacy for approval of needed services; and the availability of Title V funds to cover services outside of those reimbursed by Medicaid. For these reasons, Florida’s Title V-centered system of care for Medicaid-eligible CSHCN offers a unique and promising managed care model for this vulnerable population.
Appendix A: Key Informant List
Appendix A: Key Informant List

The following persons were interviewed by researchers of the National Policy Center for Children with Special Health Care Needs in their study of the Florida’s CMS Network:

Agency for Health Care Administration

    Bob Sharpe
    Wendy Leader Johnston
    Gail Connolly (Part C specialist)

    Stanley Graven, University of South Florida
    Pat Grosz, University of South Florida
    Judy Summers, University of South Florida

All Children’s Hospital

    J. Dennis Sexton

    Healthy Kids Program

Children’s Medical Services

    Phyllis Siderits
    Joanne Angel, Tampa Office
    Georgia Wilcox, Tallahassee Office
    Tom Nurse, Parent Consultant

    Rose Naff
    Jennifer Lloyd

Department of Children and Family Services/Children’s Mental Health

    Lonnie Mann
    Sue Ross

Developmental Disabilities

    Charles Kimber
    Kathee Winstead

Department of Education

    Devon Hardy, Consultant, University of South Florida

Group of Parents of CSHCN

Part C

    John Curran, University of South Florida
Case Study: Maryland

I. Background and Introduction

A. Medicaid Managed Care and Children with Special Health Care Needs

In 1995, the State of Maryland set out to design a statewide managed care system for its Medicaid recipients. Led by the state’s Department of Health and Mental Hygiene (DHMH), the state proposed an inclusive Medicaid managed care model which called for all Medicaid recipients to be enrolled in one of several managed care organizations (MCOs) under contract with the state. In exchange for a monthly capitated payment, these MCOs would be responsible for delivering all needed services to enrolled clients.

While this model, called HealthChoice, was largely accepted by the diverse 135-member advisory committee convened by the DHMH to advise the agency on the development of its program, several significant modifications were made. In response to concerns raised by the committee about how children with special health care needs (CSHCN) and other persons with special needs would be served within a mainstream managed care system, the model was modified so that several services and narrowly-defined populations were “carved out” of MCOs participating in HealthChoice. In addition, several special populations to be served in MCOs, including CSHCN, were identified as needing specialized case management services from the HealthChoice MCOs in which they are enrolled. This case study explores Maryland’s experience in serving CSHCN under this modified mainstream managed care model.

B. Structure and Approach to State Site Visits

The information presented in this case study is based on interviews conducted by researchers of the National Policy Center for Children with Special Health Care Needs during the latter half of
In the summer of 1998, researchers conducted extensive, structured telephone interviews with state Medicaid and Title V officials regarding the development, implementation, and operational experiences of its statewide Medicaid managed care system. These interviews set the stage for and helped to structure follow-up meetings with additional informants to obtain further information about the Medicaid managed care and related systems.

During the fall of 1998, the same researchers conducted numerous in-person and telephone, individual and small-group interviews with representatives of managed care plans under contract with the Medicaid agency; children’s hospitals; the state’s Children’s Mental Health agency; Part C/Early Intervention program; and parents of children with special health care needs. Researchers also consulted with staff of the Center for Health Program Development and Management at the University of Maryland Baltimore County, which under a contract with the DHMH developed the HealthChoice waiver application and assisted in the program’s implementation. (A list of interviews is included in Appendix A.) Each of the interviews was guided by one of several structured protocols targeted to the particular orientations of the interviewee.

C. Organization of Report

The remainder of this report is divided into two sections:

- Section II provides a detailed summary of the structure and operation of Maryland’s Medicaid managed care system, particularly as it relates to CSHCN. Discussions of eligibility, identification, and enrollment; primary care; specialty care; case management; and the range of other services provided by the program and related systems of care are included.

- Section III discusses lessons learned from Maryland’s early experience in operating its statewide Medicaid managed care system. Lessons regarding the development and operation of a managed care model responsive to the needs of chronically ill children, such as those related to identification of CSHCN, financing, family involvement, and executive-level interagency coordination, are included.
II. The Model

A. Overview of Model

In 1996, Maryland applied for and received its 1115 waiver approval from the federal Health Care Financing Administration to operate its Medicaid managed care system, called HealthChoice. The program was launched on July 1, 1997.

The managed care model implemented by Maryland is a modified mainstream managed care model; that is, but for a few limited population groups, most everyone is served by one of eight managed care organizations24 contracted to serve the program’s approximately 340,000 enrollees, about 67 percent of whom are children. Of the HealthChoice population which is not enrolled in MCOs, the one most relevant to a discussion of children with special health care needs is that comprised of persons eligible for the state’s Rare and Expensive Case Management (REM) program which was designed to remove persons with chronic, complex medical conditions who need ongoing management and whose care is very expensive from mainstream managed care.25 A Medical Review Panel, made up of five physicians and one advocate, makes recommendations to DHMH on which diagnoses to include as REM conditions. The Panel periodically reviews and makes recommendations to adjust this list, which is composed primarily of pediatric diagnoses. While all persons eligible for REM were initially required to enroll in the program, they now have the choice of enrolling in REM or in one of the contracted

---

24 The state contracted with all plans that met the criteria established for HealthChoice MCOs.

25 Populations not included in HealthChoice include: individuals who are also eligible to receive Medicare benefits; individuals whose Medicaid eligibility is based solely on a determination that the individual is medically needy under “spend down;” individuals whose Medicaid eligibility is certified for a period of less than 6 months; individuals who have been, or who are expected to be, institutionalized more than 30 successive days in a long-term care facility or an Institution for Mental Disease; individuals institutionalized in an intermediate care facility for mentally retarded persons; individuals enrolled in the Home Care for Disabled Children under a Model Waiver Program, the Family Planning Waiver Program, or the Maryland Kids Count Program; individuals receiving Maryland Pharmacy Assistance Program Services; children receiving adoption subsidies who are covered under the parent’s private insurance; and children in state-supervised care receiving adoption subsidies who live outside the state.
mainstream managed care plans. REM program enrollees receive intensive case management services. REM providers are reimbursed on a fee-for-service basis by the Medicaid agency.

In addition to several population carve-outs, the state has also explicitly carved certain services out of managed care plans’ responsibility. Those of most relevance to CSHCN include specialty mental health services as well as services specified in children’s Individualized Education Plans (IEPs) or Individualized Family Service Plans (IFSPs) and delivered in the schools or through Children’s Medical Services community-based providers.26

Almost all recipients are served by one of the eight HealthChoice MCOs. Recognizing that some of the state’s Medicaid recipients need a more intensive level of support and attention than that typically provided by mainstream managed care plans, the state required all HealthChoice MCOs to designate a “Special Needs Coordinator” to serve as the plan’s point of contact for enrollees with special needs. Furthermore, HealthChoice MCOs are required to provide case management services to enrollees who fall into one of eight special populations identified by the state as needing this extra level of support, including CSHCN.27

Maryland’s HealthChoice program is also distinguished by the reimbursement methodology used by the Medicaid agency to reimburse MCOs. HealthChoice MCOs are paid on a risk-adjusted capitated basis to provide covered services to Medicaid recipients enrolled in their plans. More detail on the HealthChoice financing approach is provided later in this chapter.

---

26 Other carved out services include personal care services; medical day care services for adults or children; long-term care services (after the first 30 days); Healthy Start case management services for at-risk pregnant and postpartum women and children under age two years; special support services for individuals with developmental disabilities (services covered for the DD waiver); and HIV/AIDS carve-out drugs.

27 The state identified the following as special populations: children with special health care needs (such as chronic asthma, sickle cell anemia, cerebral palsy, and developmental delays), individuals with a developmental disability, individuals with a physical disability, pregnant and postpartum women, individuals who are homeless, individuals with HIV/AIDS, individuals who need substance abuse treatment, and children in state-supervised care.
B. Enrollment and Identification of Special Needs Populations

To inform Medicaid recipients about the new statewide Medicaid managed care system and assist them in enrolling with their chosen provider, the Maryland Medicaid agency contracted an enrollment broker. This broker, currently Benova, provides each eligible person with a large packet of information about the different MCOs in which they may enroll. The number of available plans varies by the region of the state, but everyone has a choice of at least two options. Persons eligible for the waiver program, all of whom are guaranteed Medicaid eligibility for a period of 6 months, are asked to call the enrollment broker to select an MCO and a primary care provider. In addition to providing this service by phone, Benova also conducts outreach in clinics and representatives will meet upon request with any recipient to discuss their enrollment options. However, as all contracted MCOs are supposed to have equal capacity to serve enrollees, the enrollment broker does not steer clients with special needs to one plan over another based on any special service capacity it may possess.

Recipients who do not select a plan are automatically assigned to one. To keep automatic assignments to a minimum, especially for CSHCN, the Medicaid agency conducted extensive outreach and training with staff of agencies who work with these vulnerable populations (e.g., Children’s Medical Services (CMS), Part C/Early Intervention, foster care) to educate them about the new managed care system and request their assistance in informing clients during the early enrollment phase. In addition, Medicaid worked in collaboration with consumer advocates to develop a brochure on HealthChoice and people with special health care needs. However, for a variety of reasons, the state has experienced a high auto assignment rate. For example, nearly 10 percent of the 300,000 enrollment packages initially sent by the state to Medicaid recipients were returned due to out-of-date addresses. By linking recipients, when possible, with providers whom they have seen in the past, the state has tried to minimize the confusion that often results from such automatic assignments; however, other factors, such as the state’s

28 All counties but one have at least three plans from which recipients may choose; one county is served by two plans. In Baltimore City, where the majority of the state’s Medicaid recipients reside, recipients may choose among eight plans.
tendency to make auto assignments on an individual-level rather than a family-level basis, have complicated the transition to HealthChoice. Furthermore, even in cases when clients did select a plan, inaccuracies in the provider directory sometimes resulted in misinformed decisions and confusion for clients, providers, and MCOs alike. Key informants, however, consistently reported that program operations have improved over time as these early challenges have been addressed. In fact, statistically valid consumer satisfaction surveys conducted by Medicaid found that most recipients were enrolled with their historic provider and were satisfied with the MCO with which they enrolled. In addition, a focused study conducted by Medicaid of children with cerebral palsy found that most recipients were receiving care from their historic primary care provider even after enrollment in an MCO.

Because MCOs are required to provide case management to children and others with special health care needs, MCOs need to identify enrollees with special health care needs. The Medicaid agency has broadly defined CSHCN as children suffering from moderate to severe chronic health conditions that have significant potential or actual impact on health and ability to function which requires special health care services, and are expected to last longer than 6 months.\(^{29}\) This definition not only encompasses SSI recipients but a much larger group of children who meet this relatively broad definition of CSHCN. Medicaid officials estimate that, using this definition, 50,000 children, or 30 percent of children on Medicaid, are considered to have special health care needs—far more than the 12,000 children who are on SSI.

However, systematically identifying children who meet this definition of having a special health care need has been challenging. To facilitate MCOs’ identification of persons, including CSHCN, who may be in imminent need of health care services at the time of entry into an MCO, the state requires the use of two key identification tools, a health risk assessment form and an initial health visit, as described below:

- Health risk assessment form. Enclosed in each enrollment package sent to Medicaid eligibles is a health risk assessment form used to identify recipients with special or ongoing health care needs. Enrollees are asked to complete the

form, which includes a series of eight questions regarding health needs, and return it to Benova (or complete the form with the enrollment broker by phone) when enrolling in a managed care plan. MCOs are required to arrange for an expedited appointment, within 15 business days, for recipients who indicate through their responses on the form that they have an urgent or ongoing medical condition or concern. (A copy of the form is included as Appendix B.)

- **Initial health visit.** MCOs are required to schedule an initial appointment for new enrollees within 90 days of the date of enrollment. However, if an urgent or ongoing need is identified through the health risk assessment form, then the visit must be provided within 15 days. The state included this requirement for an initial health visit soon after enrollment to ensure that special needs identified through the health risk assessment form are verified and that CSHCN and other special populations receive case management services.

In addition to these required approaches for identifying enrollees with special needs, MCOs also employ their own strategies, including reviewing hospital discharge, claims, and pharmaceutical data that help to identify enrollees with special health care needs.

Identification of children eligible for the REM program is more straightforward than identifying children considered to have a special health care need under the HealthChoice program. Children eligible for REM are easily defined by whether or not they have any of the identified REM conditions. MCOs routinely ask primary care providers to use their own methods to identify patients with REM diagnoses so that these clients can be offered the option of enrolling in the REM program.

**C. Primary Care**

At the core of the HealthChoice program is a strong medical home model with primary care at its center; that is, each recipient is linked to a primary care provider who is responsible for providing and referring for services covered under the HealthChoice program. In keeping with Maryland’s historical focus on Medicaid’s Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program in efforts to ensure the availability of high-quality services for

---

30This requirement is excused if a new enrollee is assigned to a primary care physician who concludes that there is not a need for an initial appointment.
low-income children, the state has also made EPSDT a focal point of the HealthChoice program. Under HealthChoice, MCOs are required to provide medically necessary and appropriate EPSDT services, in accordance with recommended periodicity schedules, designed to identify and address health and developmental problems at an early stage. In addition, primary care providers for children must be certified by the state as EPSDT providers, or refer the children to a provider who is EPSDT certified.

For parents of CSHCN, however, identifying appropriate primary care providers for their children often remains a difficult task, as MCO provider directories tend not to identify primary care providers with expertise in the care of CSHCN. However, the state does allow for specialists who have been certified as EPSDT providers to serve as primary care providers for CSHCN.

D. Specialty Care

In developing the HealthChoice program, Maryland officials included several provisions to ensure that enrollees with special health care needs, especially children, would have access to the range of needed specialty services. As described below, these provisions relate to the makeup of the provider network, the range of covered services, and policies intended to smooth the transition to managed care:

- Provider network. To ensure that all enrollees would have equal access to specialty services and that health plans would be competing on a level playing field, each MCO contracted by the state was required to demonstrate its inclusion of an extensive array of specialty providers in its network, including pediatric subspecialists to care for children with special health care needs. Furthermore, if an MCO cannot demonstrate adequate capacity within its own network to deliver services needed by one of its enrollees, the state requires the plan to pay an appropriate non-participating provider to deliver the needed services.

Reports by MCOs indicated that the state’s firm requirements for specialty providers enhanced the comprehensiveness of their provider networks, for example, by spurring the development of contractual relationships with one or more of the state’s respected children’s specialty institutions (e.g., Mt. ...)
As of January 1999, the CMS program began covering certain “wraparound” services (non-medical care services not covered by clients’ insurance programs) for children in the CMS program, many of whom are in HealthChoice. Covered wraparound services include nutritional counseling and non-case management social work (e.g., counseling for adolescents with chronic conditions regarding regulation of diet and medication, body image issues, etc.).


32 As of January 1999, the CMS program began covering certain “wraparound” services (non-medical care services not covered by clients’ insurance programs) for children in the CMS program, many of whom are in HealthChoice. Covered wraparound services include nutritional counseling and non-case management social work (e.g., counseling for adolescents with chronic conditions regarding regulation of diet and medication, body image issues, etc.).
While the above policies laid a solid foundation for ensuring access to specialty services for HealthChoice enrollees, the small group of parents/parent advocates interviewed for this study indicated that managed care’s requirements for preauthorizations have complicated the process of arranging for specialty services for CSHCN, especially for children who receive care from specialty centers like the Kennedy Krieger Institute where multiple services are typically provided in one day. Since preauthorizations for specialty services can take several days, parents and primary care providers must try to anticipate what services will be needed and obtain needed prior authorizations in advance of visits, whereas prior to managed care certain specialty services such as x-rays for orthopedic visits were routinely provided without prior authorizations.33

Given these issues, these parents, not surprisingly, indicated a preference for the less restrictive fee-for-service system, such as that offered by the REM program. However, some REM enrollees have been reported to experience more limited access to providers than HealthChoice enrollees. Key informants attributed this problem to low fee-for-service reimbursement rates paid to REM providers by the Medicaid agency. Under current policy, REM providers receive the same rates paid to Medicaid fee-for-service providers, despite the more intense needs of REM enrollees. Because some MCOs have been paying providers a higher rate, providers are occasionally reluctant to take care of a REM patient who was previously in an MCO which paid the provider a higher rate. For this and other reasons, some parents with REM eligible children did not want to participate in the program, as required early in HealthChoice; however, this policy was changed so that persons with REM conditions now have the option of enrolling in REM or one of the eight HealthChoice MCOs.

Similar to CSHCN around the country, CSHCN in Maryland (including children served by MCOs and in REM) continue to experience problems in accessing specialty services in rural areas. Although Maryland has several outstanding specialty pediatric care centers, these are

33Interestingly, one of the MCOs interviewed for this study indicated that it was planning on eliminating prior authorization requirements for most services and supplies, since (as indicated by parents and providers) these are generally being approved anyway. With the reduction of prior authorization requirements for all but inpatient hospital stays and certain outpatient surgeries, this MCO expects to save the significant administrative costs incurred by the review and approval of prior authorization requests for many services.
generally located in Baltimore, which means that families living in remote areas must make time-consuming trips with their children for needed services. (The problems noted above with getting quick approval for unanticipated specialty services becomes particularly problematic during these visits to distant providers.) Parents noted that access to providers for children in rural areas has improved somewhat under HealthChoice as compared to the fee-for-service system, but they also indicated a strong need for more satellite clinics in rural areas.

E. Case Management

Case management is a central component of the state’s approach for ensuring that special populations, including chronically ill children, receive needed services within the mainstream managed care system. Although MCOs commonly employ case management staff to serve a gatekeeping and utilization review function, the case management required by the state under HealthChoice is intended more as a strategy for linking clients to needed services. The state has identified several vulnerable, or “special” populations—one of which is CSHCN—that are to receive case management services by HealthChoice MCOs. This case management requirement was designed to address concerns that MCOs provide the extra level of attention and assistance needed by vulnerable populations.

As a foundation for the case management services to be provided by MCOs, Maryland requires each HealthChoice MCO to designate a “Special Needs Coordinator” to serve as the plan’s point of contact for persons within the identified special population groups as well as to be a liaison with the Medicaid agency on issues related to special needs populations. Special Needs Coordinators are generally nurses with various levels of experience and knowledge about CSHCN. To enhance the effectiveness of the Special Needs Coordinators, Medicaid sponsors ongoing monthly educational meetings addressing issues related to special needs populations and their participation in the HealthChoice program.

The type of case management to be provided to CSHCN, as a designated special population, is generally left to the discretion of the MCOs, as regulations only provide a limited definition of
case management as “assessing, planning, coordinating, monitoring, and arranging the delivery of medically necessary and appropriate health-related services.”\textsuperscript{34} The significant leeway granted to MCOs to design their own case management approaches has resulted in considerable variation in the type of case management systems that have been implemented by the different MCOs, such as staff qualifications and caseload sizes. For example, some MCOs have case managers on staff, others contract with community-based organizations to deliver case management services, while others employ a combination of these approaches for providing case management services across their service areas. MCOs’ approaches to assigning patients to case managers also varies—in some plans, case managers work with clients with any number of different conditions, whereas other MCOs link clients with certain conditions with case managers who have expertise in those areas.

While these differences in case management approaches exist, several similarities also emerged in discussions with key informants, including the following:

- Most client contact with case managers occurs over the telephone, although home visits are also provided in complicated cases.
- MCOs acknowledge the importance of taking a holistic approach to case management but also, not surprisingly, indicate that case managers spend most time attending to clients’ medical needs and coordinating their medical care.
- MCOs generally do not make case manager assignments by age, meaning that case managers tend to work with a mixture of children and adults rather than specializing in children with special needs.

In contrast to MCO enrollees, clients who are enrolled in the REM program receive case management services from one of several case management agencies. Once again, significant variation in the level and quality of services provided to clients by the different REM case management contractors was also reported by key informants. However, reflective of the REM program’s mission to provide a more intensive level of case management services than that

delivered by HealthChoice MCOs, most case management provided under the REM program was characterized as being delivered in person rather than by telephone.

The few parents interviewed for this study supported the state’s intent of providing case management services to families with CSHCN. However, like other key informants, they also reported significant variability in case management capacity and noted that, due to the backlog of cases in some plans, not all parents with CSHCN had yet heard from their HealthChoice MCOs about the provision of case management services. Variation in the type and intensity of case management services provided across the HealthChoice MCOs, as well as between the MCOs and the REM program, led in 1998 to the establishment of a Case Management Task Force as a sub-group of the Special Needs Children Advisory Council to make a recommendation to the Department of Health and Mental Hygiene on “ideal” case management services to CSHCN in HealthChoice and REM. State officials report that the recommendations of the Task Force were well received by the DHMH Secretary and forwarded to the MCOs for implementation.

F. Links to Other Systems

As indicated earlier, Maryland has carved out several services of importance to CSHCN from the responsibility of HealthChoice MCOs, namely mental health services and those included under children’s IFSP/IEPs. This section describes the delivery of these services under Maryland’s Medicaid managed care program.

1. Mental Health Services

Based on input received from its advisory committee, DHMH did not include mental health services among the services to be provided by the private HealthChoice MCOs.\textsuperscript{35} Instead, responsibility for mental health services was maintained with the state’s public mental health

\textsuperscript{35}The mental health carve out did not include substance abuse services.
system, specifically DHMH’s Mental Hygiene Administration, which has a long history of serving Maryland’s mentally ill citizens.

Maryland’s public mental health system is divided into 24 jurisdictions (23 counties plus the City of Baltimore), each managed by a local “core service agency” (CSA). These CSAs, which serve as arms of the state Mental Hygiene Administration, have responsibility for planning and monitoring mental health services at the local level. Services provided within the public mental health system are delivered through a network of traditional public mental health clinics as well as individual providers, many of whom were added to the network with the implementation of HealthChoice. Clients of the public mental health system receive case management services by case management vendors under contract with the local CSAs, similar to the REM program. To oversee the day-to-day operations of the public mental health system and work with the CSAs, the state has contracted with an administrative services organization, Maryland Health Partners, to perform medical necessity reviews, collect data, pay claims, and perform other related administrative functions.

With the implementation of HealthChoice, the public mental health system gained explicit responsibility for meeting the mental health needs of all Medicaid recipients, including HealthChoice enrollees. However, HealthChoice MCOs have responsibility for “primary” mental health services, a term that refers to the role of primary care physicians in addressing easily-treatable mental health problems. However, patients may self-refer to the public mental health system at any time without obtaining prior authorization from their primary care physicians, up to a maximum of 12 visits. After that point, Maryland Health Partners required the patient’s primary care physician to submit a plan of care for further evaluation and treatment. To obtain approval for mental health services beyond the unmanaged 12 visits, the patient must have a DSM-IV diagnosis.

To fund the delivery of mental health services under this arrangement, Medicaid funds were transferred to the Mental Hygiene Administration. The Mental Hygiene Administration receives a set annual budget that places the agency at risk for mental health services for HealthChoice enrollees and other Medicaid recipients. In exchange for this assumption of risk for the delivery
and payment of mental health services, the Mental Health Administration has also gained flexibility. Agency officials report important program enhancements since the implementation of HealthChoice, including recruitment of additional private-sector providers, a greater focus on children’s mental health services, and expanded outreach efforts to educate Medicaid recipients about how to access mental health services.

Key informants agree that HealthChoice enrollees’ ability to access the mental health system has succeeded in facilitating linkages to mental health services. Parents, in particular, report being pleased with the ability to seek professional mental health services for their children. However, two issues identified by MCO representatives indicate that further refinements are needed:

- First, while MCO representatives report that their enrollees are experiencing good access to mental health services, they also note ongoing problems with getting information about mental health services provided to their enrollees. Such difficulty in communication between mental health and other providers frustrates MCOs’ ability to coordinate enrollees’ care and raises concern about the potential problems that can arise when medical and mental health providers are not in touch and, for example, prescribe medications that can negatively interact with each other. Interagency efforts to address this problem have been undertaken but have stalled due to problems resolving issues surrounding confidentiality concerns.

- Second, while the carve out of mental health services is essentially a clean one, the retention of responsibility by MCOs for primary mental health services means that the boundary between what is and is not carved out is not always clear. In particular, questions have reportedly arisen over whether attention deficit disorder is a primary mental health condition and, in turn, whether HealthChoice MCOs or the Mental Health Administration are responsible for the significant costs of prescription medication for this common condition.

2. Early Intervention and Special Education Services

For children with special health care needs, the therapy and related services provided by the Part C/Early Intervention and special education programs are an important component of their comprehensive care plans. In Maryland, the State Department of Education is the lead agency for both the Part C and special education programs. Each year, Maryland’s Part C program
serves approximately 6,000 children from birth to age three in need of developmental services, and the special education program serves approximately 104,000 children ages 3 to 21 years old who have educationally-related needs for therapy and related services. Providers of early intervention and special education services include schools, local health departments, private agencies such as the Hearing and Speech Agency, private contractors, and providers in the state’s CMS program for CSHCN.

Similar to the mental health carve out, DHMH officials decided to remove health-related and targeted case management services included in children’s IFSPs and IEPs from HealthChoice MCOs’ responsibility as long as the services were delivered in schools or with CMS community-based providers. The vast majority of IEP services are delivered in the schools. Services for children with IFSPs delivered in hospital-based programs were not carved out of HealthChoice MCO responsibility.

Maryland’s partial carve out of IFSP/IEP services is reflective of a classic difficulty of carve-out arrangements—determining where the boundaries are between the responsibility of the MCO and the provider(s) of carved-out services. With the split in responsibility for IFSP/IEP services between MCOs and community providers, questions arise about the incentives this arrangement creates for MCOs to refer to community providers for the delivery of services in IFSP/IEPs.

Another issue raised by key informants about the effectiveness of the arrangement for IFSP/IEP services relates to information exchange among providers serving the same clients. To promote integration between the Part C/special education and HealthChoice systems for dually-eligible children, Medicaid requires HealthChoice MCOs to coordinate with these other systems of care.

---

36 The Part C program serves children who have a measurable delay and a diagnosed condition with a high probability of developmental problems, as well as children with atypical development that is likely to lead to developmental delay if no intervention is provided.

37 Local health departments can bill for early intervention services if they are enrolled as CMS community-based providers.

38 CMS also funds local health departments to provide developmental pediatric clinics for infants and toddlers, which may qualify children for the Part C program.
However, variable levels of communication and integration were reported to occur between these systems, with the tendency for the special education system, in particular, to operate in parallel to the Medicaid managed care system.

G. Community-based Support Services

In addition to those public agencies discussed above, local health departments (LHDs) also have an explicit role in serving HealthChoice clients. In fact, HealthChoice MCOs are required to enter into a Memorandum of Understanding with local health departments in their service areas to facilitate their collaboration in serving HealthChoice enrollees. HealthChoice regulations identify several explicit roles for LHDs in serving enrollees including conducting outreach to non-compliant patients, arranging for transportation to service appointments, and operating an ombudsman program for investigating and addressing complaints against MCOs. Medicaid directly pays LHDs for these and other services to HealthChoice enrollees through a grant funded by Medicaid administrative matching funds.

H. Financing

With regard to financing, the HealthChoice program is among the forefront of the Medicaid managed care programs across the country due to its employment of capitated risk-adjusted payments to reimburse contracted MCOs. Maryland’s HealthChoice program is the first state Medicaid program to employ the ACG risk adjustment methodology developed by researchers at the Johns Hopkins University.

Upon enrollment in HealthChoice, each person is placed into one of four categories depending on their eligibility status: (1) families/children; (2) disabled; (3) persons with AIDS; (4) pregnant women/SOBRA mothers. Within the first two categories, separate rates are paid for persons

---

There is also a maternity/delivery supplemental payment category consisting of a one-time payment for delivery, which is paid to MCOs on top of the monthly capitated rate for pregnant women. The “SOBRA” label refers to the state’s expansion of Medicaid coverage to pregnant women through federal Omnibus Budget
who have at least six months of history under the Medicaid fee-for-service program within fiscal year 1997. Based primarily on the types and number of the diagnoses indicated by the claims history, these individuals are assigned to one of nine risk-adjusted cells (RACs). Across these 18 RACs (nine for families/children category and nine for the disabled category), the per member per month rates vary significantly, from $53 for the lowest RAC to $754 for the highest RAC within the families/children category, and from $167 for the lowest RAC to $2,060 for the highest RAC in the disabled category.\textsuperscript{40} Individuals without the requisite claims history in the Medicaid fee-for-service program are assigned to a geodemographic rate cell determined by the person’s age (under 1, 1-5, 6-14, 15-20, 21-44, 45+), gender, and location either within or outside of Baltimore City. Thus, all individuals in the families/children and disabled categories are assigned to one of 62 rate cells based on either past claims history or geodemographic factors.\textsuperscript{41} Individuals’ assignment into rate cells is adjusted on an annual basis.

Upon enrollment, plans are paid the appropriate monthly capitated rate for each client. The capitated per member per month rates were developed based upon the Medicaid fee-for-service claims data. The rates paid to HealthChoice MCOs during fiscal year (FY) 1998 were based upon FY 1995 Medicaid fee-for-service claims data, FY 1999 rates were based upon FY 1996 claims data, and FY 2000 rates will be based upon FY 1997 claims data. (As Medicaid FFS claims data will be considerably less available after FY 1997, when Medicaid fee-for-service billing was largely phased out with the implementation of HealthChoice, the state is in the process of identifying a new approach for developing risk-adjusted rates.) In exchange for the capitated payments, MCOs are responsible for providing or arranging for all of their enrollees’ needed care. However, MCOs are protected from excessive losses by a stop-loss provision which limits MCOs’ liability for hospital inpatient costs over $61,000 for any enrolled individual. The state pays 90 percent of the costs in excess of this amount, and the MCO pays the remaining 10 percent.

\textsuperscript{40}Maryland collapsed more than 80 separate ACGs identified by Johns Hopkins University into 18 RACs by grouping diagnoses with comparable costs.

\textsuperscript{41}Rates paid to persons in the other two eligibility categories—for persons with AIDS and pregnant women eligible through SOBRA, vary only by location within or outside of Baltimore City.
Overall, MCOs reported being very pleased with the Medicaid agency’s payment of risk-adjusted rates as a means of compensating plans for the extra costs involved in caring for chronically ill and disabled children. However, key informants generally agreed that further refinements are needed in the state’s risk adjustment methodology. In particular, MCO representatives identified a desire for more enrollees, namely those without the required history of claims experience with the Medicaid program, to be classified into RACs based on their diagnoses. Many enrollees who do not have claims history with the state do have conditions which require expensive care but are placed in rate cells based on geodemographic factors. Key informants also indicated that numerous plans have had financial difficulties as HealthChoice providers and that others that are doing well may have to decrease payment for services they provide with an upcoming expected cut in fees.\textsuperscript{42} Because MCOs’ financial health is of critical importance to the HealthChoice program, it will be necessary to assess how well the risk adjustment reimbursement approach is working as the program gains more experience.

Another financing issue explored by the researchers had to do with MCOs’ approaches to paying primary and specialty care providers within their own networks. While the HealthChoice MCOs all receive a capitated payment from the Medicaid agency, their approaches to paying their providers varies, as indicated below:

\begin{itemize}
  \item **Payments to primary care providers.** Most HealthChoice MCOs generally pay primary care providers subcapitated rates. However, one plan reported having recently switched to fee-for-service payments in an effort to preserve encounter data, as encounter data are expected to be used by the state to determine risk-adjusted payment rate determinations and are important in plan quality assurance efforts. Another fundamental reason for making this switch was to provide primary care providers with an incentive to see patients, which the MCO believes will reduce the costs of specialty care.
  \item **Payments to specialty providers.** MCOs generally pay specialists on a fee-for-service basis (typically at higher rates than those paid under the REM program). However, a few plans pay (or are considering paying) specialists on a subcapitated basis.
\end{itemize}

\textsuperscript{42}In July 1998, a miscalculation in Medicaid payment rates that resulted in excess payments of $90 million to the HealthChoice MCOs was discovered. While independent auditors were to review the situation and determine if the higher payments were justified, a fee cut was widely expected. However, this did not occur.
Given this variation and the changing approaches being tried by MCOs, it seems apparent that plans are still learning about the best ways to reimburse their providers for services rendered to plan enrollees.

Finally, with respect to the REM program, it appears that the rates being paid by the Medicaid agency are not adequate to entice a sufficient number of providers to serve REM clients. In fact, as indicated earlier, the low reimbursement rates being paid to REM providers was identified by key informants as a barrier to care for this population. Thus, fee-for-service payment arrangements cannot be presumed to ensure that chronically ill and disabled children will be guaranteed the desired level of access to care.

III. Lessons Learned Regarding Service Integration

Maryland’s early experience in operating its Medicaid HealthChoice program offers many interesting lessons about serving CSHCN through a largely mainstream managed care arrangement. This section discusses lessons learned regarding state-level efforts at interagency coordination, family involvement, systems for enrollment and identification, information sharing, service coordination, and quality assurance.

A. State-Level Efforts at Interagency Coordination

Maryland has a strong history of interagency collaboration, facilitated by the co-location of Medicaid, public health and its Title V/Maternal and Child Health program, mental health, and other health agencies within the Department of Health and Mental Hygiene. In keeping with this tradition, many state agencies were actively involved in the development and implementation of the HealthChoice program. In particular, Medicaid officials looked to its sister agencies to ensure that HealthChoice would meet the special needs of the vulnerable populations they serve, such as CSHCN, to be served under the new program. The development of regulations addressing the care of special populations under managed care as well as the structure of the HealthChoice program—namely, the mental health agency’s role in
providing mental health services and the role of LHDs in providing outreach, transportation, and ombudsman services—reflects the importance of interagency collaboration not only in the development, but also the ongoing operation, of the HealthChoice program.

While the Medicaid and mental health agencies have a history of coordination, their level of collaboration in serving Medicaid clients has reportedly increased since the implementation of HealthChoice. This increased level of coordination has been spurred by the mental health agency’s assumption of risk and responsibility for the mental health service needs of Medicaid recipients, as well as the accompanying transfer of Medicaid funds into the mental health agency’s budget.

B. Family Involvement in System Planning, Implementation, and Oversight

In developing and implementing the waiver program, DHMH sought input from a broad range of interested parties including families. One of the central ways that Maryland has involved families has been through the numerous advisory groups convened to steer the development and ongoing operation of HealthChoice. These include the Special Needs Children Advisory Council, which advises Medicaid on policies to improve the care of CSHCN under HealthChoice, and the Case Management Task Force, which has developed recommendations for enhancing and standardizing case management provided to special populations by HealthChoice MCOs.

Although advisory committees represent an important strategy for the state, as well as MCOs, to obtain input from families, state officials acknowledge that this approach has its limitations. Families may not feel comfortable participating in such settings, and finding convenient meeting times and locations that work for families and other members of the committees can often present logistical challenges. In recognition of these limitations, the agency has also convened several recipient focus groups during the waiver development and implementation process and report that these forums have offered a more conducive setting for obtaining family input.
On the service delivery level, informants identified families’ role in the development of service delivery plans as a critical mode for involving families in decision-making. Direct enrollee input received by MCOs and the Medicaid agency also impact policy and programmatic decisions. For example, a parent interviewed for this study noted that her child’s MCO added a local durable medical equipment vendor to its network in response to complaints from parents on the state’s eastern shore about having to use an inconvenient, centrally-located supplier.

Despite having these modes for obtaining family input, state representatives and families alike acknowledged the challenge of routinely involving families in decision-making and noted the need to find more creative and effective ways for obtaining this critical input.

C. Systems for Enrollment and Identification

In implementing the HealthChoice program, Maryland encountered significant challenges that have had direct implications on the enrollment and identification of CSHCN. As discussed earlier, the state mailed information about HealthChoice to all eligible persons and requested that they select a plan in which to enroll. The small group of parents and advocates interviewed for this study indicated that, for a variety of reasons, carrying out this request was often difficult. For example, not only did many people not even receive their information packets—it was noted earlier that 10 percent of enrollee information packets were returned to the Medicaid agency—but those who did often found the enrollment packet to be confusing. While the Medicaid agency took care to ensure that adequate information was provided to recipients to facilitate their choice of MCOs, parents reported that the large amount of information included was often overwhelming. While such problems could have affected all enrollees, they were perhaps particularly concerning for families with CSHCN given these children’s more intensive and immediate needs for services. For example, parents of CSHCN reported difficulty in obtaining guidance in how to select from among multiple MCOs due to several factors, including: the enrollment broker hotline was typically busy, hotline staff were often not knowledgeable about CSHCN, and other suggested sources of guidance like LHD staff were variably informed about the HealthChoice program. For these and other reasons, many people
did not choose a plan and were assigned one by the state, resulting in confusion for recipients as well as MCOs and their providers as to which recipients were enrolled in which plan. This situation, in turn, created significant challenges in ensuring the smooth delivery and payment of services. Key informants interviewed for this study noted that such problems could likely have been minimized if implementation had been phased in over several months. Some also noted that the large number of MCOs included in HealthChoice exacerbated implementation problems and increased the complexity of, and administrative costs associated with, the overall system. Despite this range of reported implementation problems, however, studies conducted by Medicaid found that most recipients were enrolled with their historic providers.

The complications of the enrollment process also affected MCOs’ ability to identify children and others with special health care needs to whom they are required to provide case management services. As discussed earlier in this chapter, the state developed a Health Risk Assessment (HRA) form to identify CSHCN and other persons in one of the seven special population groups and included it as part of the enrollment process. Unfortunately, a large portion of enrollees did not complete the form, hindering MCOs’ ability to quickly identify new enrollees with pressing health care needs.

The state’s development and implementation of the HRA is reflective of Maryland’s commitment to ensuring that HealthChoice MCOs can identify and, thus, provide case management services to persons with special health care needs. The HRA represents an important development in efforts to promote mainstream managed care plans’ ability to identify enrollees with special needs and illustrates the capacity of organized managed care systems to systematically assess patient needs. MCO representatives indicated that the HRA functions well as a trigger for further inquiries to enrollees regarding their health, especially when used in combination with the follow-up exam required by the state. However, there is widespread agreement that the nature of the questions included on the form are too broad in scope, leading to many “false positive” determinations, while at the same time often missing CSHCN who are not identified as such by parents completing the form. In response to these concerns, the form was in the process of being revised during the course of this study. However, in light of the
limitations of a screening form, MCOs emphasized the need for strong internal information management systems for identifying CSHCN.

In contrast to the challenges of identifying special needs children in HealthChoice, identification of children eligible for the REM Program is much more straightforward given the program’s use of diagnosis-based eligibility criteria. While the identification of these children is clear, the more fundamental issue with regard to REM is whether those children with one of the identified REM conditions should be carved out of HealthChoice MCOs. A common criticism of the REM eligibility approach is that the list of REM conditions does not necessarily identify those with the most severe needs, as persons with a given condition can be differentially affected and, therefore, have varying levels of need for ongoing care. Interviewees agreed that REM should be better targeted to people who have problems that severely affect their ability to function, regardless of the particular condition from which they suffer. Such an approach, however, would certainly complicate any rate setting methodology.

In creating the REM Program, the intent of policymakers was to provide high quality case management services for recipients with rare and expensive conditions. Key informants indicated that political pressure has led to an increase in the size and scope of REM. Over time, numerous conditions have been added to the REM eligibility list and, in fact, the first review and modification of REM-eligible conditions effective as of July 1998 resulted in a significant expansion of the REM population.

D. Systems for Information Sharing

In discussing patterns of information sharing under HealthChoice, key informants expressed a large degree of consensus that, while service carve outs may make sense for some reasons—such as easier access to the carved out services and the delivery of these services by providers with particular expertise in the field—they tend to hinder the effective flow of information between the range of providers serving a particular client. In the words of one informant: “if it’s carved out, we forget about it.” For example, although mental health officials
reported that their provider contracts require information on services provided to HealthChoice enrollees to be shared with primary care providers, there are no formal mechanisms for agency oversight to ensure that this occurs and, in fact, MCO representatives reported consistent problems in getting such information from mental health providers. Informants agreed that strong systems need to be in place to promote information exchange.

E. Systems for Service Coordination

In developing its HealthChoice program, Maryland officials built on the widespread consensus among health professionals that care coordination is a critical component of service delivery systems for populations with special needs. As discussed earlier in this report, HealthChoice MCOs are required to have two key components to their service coordination systems: a designated Special Needs Coordinator and the capacity to provide case management services to CSHCN and other special populations. In addition, case management services are provided to all persons enrolled in the carved-out REM program.

The state can be praised for this strong emphasis on case management services. Key informants interviewed for this study consistently reported that the state’s requirements around case management for CSHCN and other “special populations” has helped to bring a new level of focus to these vulnerable populations within the mainstream managed care system. With regard to the Special Needs Coordinator, Medicaid officials and MCOs alike have found that having a designated staffperson in this role helps to facilitate MCOs’ relations with the Medicaid agency and enhance their understanding of Medicaid’s expectations and requirements with regard to special populations. In addition, having a clearly identifiable person serving as the Special Needs Coordinator appears to facilitate enrollees’ ability to get information about and access to needed services, while also facilitating coordination with other systems of care serving MCO enrollees by having a clear point of contact for communication and information.

Nonetheless, key informants also indicated that the current approach to case management is not working as well as intended, at least for CSHCN. As indicated earlier, parents and others report that HealthChoice MCOs are experiencing significant backlogs in cases. Therefore, not
only are some clients not receiving the level of contact that may be required with their case
managers, but others have not even been contacted by their MCOs about receiving case
management services. Some key informants suggested that staff-client ratios for both Special
Needs Coordinators and case managers could help to address this problem.

Interviews with key informants regarding the case management approach employed under
HealthChoice also identified varying opinions about whether case managers for CSHCN should
be primary experts in how to provide comprehensive case management services or, on the other
hand, have primary expertise in the diseases affecting their clients (a disease management
approach). While certain groups with disease-specific expertise are HealthChoice case
management entities, the HealthChoice approach primarily reflects the state’s position that
case managers are most effective when they are primarily experts in how to provide
comprehensive case management services and when they work with specialists (e.g., children’s
specialty institutions, CMS) to get the disease specific information that they need.
Representatives of children’s specialty institutions indicated that a downside of this approach
from their perspective is that HealthChoice and REM case managers place significant demands
upon their staff for assistance in case managing clients with complicated health problems, time
that is unreimbursable since Title V funding traditionally provided to children’s specialty
institutions for disease-oriented case management was lost upon implementation of
HealthChoice. The report by the Case Management Task Force mentioned earlier addressed
this issue, noting the need for more formal relationships to be outlined with respect to how
existing disease management expertise in Maryland’s centers of excellence should be utilized by
MCO and REM case managers, “whether through cooperative agreements, subcontracting, or
other appropriate mechanisms.”

F. Systems for Quality Assurance, Monitoring, and Oversight

43 HERO, which serves HIV patients, is a REM case management contractor.

To ensure that children are receiving recommended screening services and being treated for identified health conditions, as required by Medicaid’s EPSDT program, the state has traditionally utilized an EPSDT nurse team to conduct quality assurance reviews in provider offices. This approach has been continued under HealthChoice and serves as an important avenue for monitoring systems of care for all children, including CSHCN.

However, in recognition of the need for more focused attention on how CSHCN are being cared for under the new Medicaid managed care system, the HealthChoice regulations allow the DHMH to conduct focused studies on CSHCN being served through MCOs to assess MCO referral practices; the delivery of timely, medically necessary, and appropriate services; and the quality of services rendered. In the first year of HealthChoice, the Medicaid agency had identified three populations of CSHCN—those with cerebral palsy, asthma, and sickle cell anemia—to be the subject of special studies. Medicaid officials note that these focused studies will be an important vehicle for raising attention to the care of special populations under the HealthChoice program.

In addition to special studies undertaken by the state, MCOs reported using their own information management systems as a valuable quality oversight tool. In fact, a pediatrician interviewed for this study reported that one of the HealthChoice MCOs in which he participates sent him a list of his asthma patients who did not have prescriptions filled for inhaled steroids, the standard of care for this condition. This example demonstrates the excellent use to which MCOs can, and apparently do, put their information systems to use to promote high-quality care for their enrollees.

G. Conclusion

This study of Maryland’s HealthChoice program offers important insights into one state’s approach to designing a mainstream managed care system that is responsive to the needs of special populations, including CSHCN. As has been discussed throughout this report, Maryland has taken a variety of steps to accomplish this important goal, including:
Utilization of a Health Risk Assessment Form, combined with an initial health visit, to identify enrollees with special and ongoing health care needs;

The requirement that each HealthChoice MCO designate a Special Needs Coordinator to serve as the plan’s central point of contact for enrollees and providers regarding services for CSHCN and other special populations identified by the state;

The requirement that HealthChoice MCOs provide case management services to CSHCN and other special populations;

The use of risk-adjusted capitation rates that are tied to enrollee diagnoses; and

The provision of special studies to assess the care of CSHCN under HealthChoice.

Although further refinements of these approaches are needed, key informants agree that these tools have collectively served to raise the level of attention to CSHCN above that which normally exists within mainstream managed care plans and systems, a noteworthy accomplishment of the HealthChoice program.

The HealthChoice model is a complicated one, with a variety of populations and services carved out from MCO responsibility. While these carve outs were created in response to concerns about the needs of special populations, this study indicates that service carve outs are likely to further complicate the integration of services delivered by different providers. Furthermore, Maryland’s experience with the REM Program suggests that, contrary to common perception, access to providers is not necessarily better under fee-for-service as compared to managed care arrangements, at least where fee-for-service reimbursement levels are insufficient to encourage providers’ participation. Perhaps additional experience under the HealthChoice program will help to discern whether the service and population carve-out arrangements are, indeed, the best approach to meeting the needs of the state’s Medicaid recipients with special needs or if, instead, further integration of all populations and services within contracted MCOs is warranted.
Appendix A: Key Informants
Appendix A: Key Informants

The following persons were interviewed by researchers of the National Policy Center for Children with Special Health Care Needs in their study of the Maryland’s HealthChoice Medicaid managed care program:

Department of Health and Mental Hygiene

  Susan Tucker, Medical Assistance
  Nira Bonner, Children’s Medical Services
  Al Zachik, Children’s Mental Health
  Freddie Herbert, Children’s Mental Health

  Mark Smolarz, Prudential Health Care Plan
  Part C/Early Intervention and Special Education

Center for Health Program Development and Management,
University of Maryland Baltimore County

  Mary Mussman
  Kathy Koontz

Children’s Specialty Institutions

  George Dover, Johns Hopkins Hospital
  Gary Goldstein, Kennedy Krieger Institute

  Debbie Metzger, Part C/Early Intervention
  Tom Stengel, Baltimore County Health Department
  Vera Froehliger, Consultant to Department of Education

  Pediatric Provider

Consumer Organizations/Parents

  Susan Tager, Families Involved Together, Inc.
  Josie Thomas, The Parents’ Place of Maryland, Inc.
  Small Group of Parents/Parent Advocates affiliated with Parents’ Place of Maryland, Inc.

HealthChoice Managed Care Organizations

  Donald Blanchon, Maryland Physicians Care
  Kathy Trostle, HelixCare

  Crossan O’Donavan, Former President of American Academy of Pediatrics
To assist your chosen MCO in deciding how soon you may need to see a doctor or nurse and to find out what health care services you need, please answer the following questions. Use the column labeled “Head of Household” to answer the questions for yourself. For each other family member to be enrolled, place the answers to the questions in the column labeled “Family Member 1”, Family Member 2, Family Member 3. If you need additional space for extra family members, please use another form.

<table>
<thead>
<tr>
<th>Health Questions</th>
<th>Head of Household</th>
<th>Family Member 1</th>
<th>Family Member 2</th>
<th>Family Member 3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Today's Date:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Write in Name:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Medical Assistance Number:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. <strong>Are you (or a family member) taking any prescription medications that need to be refilled?</strong></td>
<td>Within 1 week</td>
<td>Within 1 week</td>
<td>Within 1 week</td>
<td>Within 1 week</td>
</tr>
<tr>
<td></td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td></td>
<td>Within 1 month?</td>
<td>Within 1 month?</td>
<td>Within 1 month?</td>
<td>Within 1 month?</td>
</tr>
<tr>
<td></td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td></td>
<td>Within 1-2 months?</td>
<td>Within 1-2 months?</td>
<td>Within 1-2 months?</td>
<td>Within 1-2 months?</td>
</tr>
<tr>
<td></td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
</tr>
</tbody>
</table>
### Health Questions

<table>
<thead>
<tr>
<th></th>
<th>Head of Household</th>
<th>Family Member 1</th>
<th>Family Member 2</th>
<th>Family Member 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.</td>
<td>Are you (or a family member) using any medical equipment or supplies that need to be renewed?</td>
<td>Within 1 week</td>
<td>Within 1 week</td>
<td>Within 1 week</td>
</tr>
<tr>
<td></td>
<td>within 1 week?</td>
<td>no</td>
<td>no</td>
<td>no</td>
</tr>
<tr>
<td></td>
<td>yes</td>
<td>no</td>
<td>no</td>
<td>no</td>
</tr>
<tr>
<td></td>
<td>within 1 month?</td>
<td>no</td>
<td>no</td>
<td>no</td>
</tr>
<tr>
<td></td>
<td>yes</td>
<td>no</td>
<td>no</td>
<td>no</td>
</tr>
<tr>
<td></td>
<td>within 1-2 months?</td>
<td>no</td>
<td>no</td>
<td>no</td>
</tr>
<tr>
<td></td>
<td>yes</td>
<td>no</td>
<td>no</td>
<td>no</td>
</tr>
<tr>
<td>3.</td>
<td>Do you (or a family member) have any of the following health problem(s)?</td>
<td>Asthma</td>
<td>Asthma</td>
<td>Asthma</td>
</tr>
<tr>
<td></td>
<td>cerebral palsy</td>
<td>no</td>
<td>no</td>
<td>no</td>
</tr>
<tr>
<td></td>
<td>diabetes</td>
<td>no</td>
<td>no</td>
<td>no</td>
</tr>
<tr>
<td></td>
<td>heart disease</td>
<td>no</td>
<td>no</td>
<td>no</td>
</tr>
<tr>
<td></td>
<td>high blood pressure</td>
<td>no</td>
<td>no</td>
<td>no</td>
</tr>
<tr>
<td></td>
<td>sickle cell disease</td>
<td>no</td>
<td>no</td>
<td>no</td>
</tr>
<tr>
<td></td>
<td>lead poisoning</td>
<td>no</td>
<td>no</td>
<td>no</td>
</tr>
<tr>
<td></td>
<td>other</td>
<td>no</td>
<td>no</td>
<td>no</td>
</tr>
</tbody>
</table>

**Circle all that apply**
<table>
<thead>
<tr>
<th>Health Questions</th>
<th>Head of Household</th>
<th>Family Member 1</th>
<th>Family Member 2</th>
<th>Family Member 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. Have you (or a family member) been seeing or scheduled to see a doctor, nurse or clinic?</td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td></td>
<td>What is the doctor, nurse or clinic’s name?</td>
<td>What is the doctor, nurse or clinic’s name?</td>
<td>What is the doctor, nurse or clinic’s name?</td>
<td>What is the doctor, nurse or clinic’s name?</td>
</tr>
</tbody>
</table>
5. Members of certain groups need special services. Are you (or a family member) a member of any one of the special needs groups listed below?

<table>
<thead>
<tr>
<th>Health Questions</th>
<th>Head of Household</th>
<th>Family Member 1</th>
<th>Family Member 2</th>
<th>Family Member 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have a child with a special health care need</td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Have a developmental delay, or are homeless</td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Have a physical disability or have HIV/AIDS</td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td></td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
</tr>
</tbody>
</table>

6. Does a health care worker come to your house? | □ Yes □ No | □ Yes □ No | □ Yes □ No | □ Yes □ No | □ Yes □ No |
<table>
<thead>
<tr>
<th><strong>Health Questions</strong></th>
<th><strong>Head of Household</strong></th>
<th><strong>Family Member 1</strong></th>
<th><strong>Family Member 2</strong></th>
<th><strong>Family Member 3</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>7. Are you (or a family member) getting counseling for any of the following?</td>
<td>Mental Health</td>
<td>Mental Health</td>
<td>Mental Health</td>
<td>Mental Health</td>
</tr>
<tr>
<td></td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td></td>
<td>Alcohol use</td>
<td>Alcohol use</td>
<td>Alcohol use</td>
<td>Alcohol use</td>
</tr>
<tr>
<td></td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td></td>
<td>Drug use</td>
<td>Drug use</td>
<td>Drug use</td>
<td>Drug use</td>
</tr>
<tr>
<td></td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Health Questions</td>
<td>Head of Household</td>
<td>Family Member 1</td>
<td>Family Member 2</td>
<td>Family Member 3</td>
</tr>
<tr>
<td>-----------------</td>
<td>-------------------</td>
<td>-----------------</td>
<td>-----------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>8. Are you (or a family member) pregnant or have you had a baby in the past 2 months?</td>
<td>□ Yes □ No □ Not Applicable</td>
<td>□ Yes □ No □ Not Applicable</td>
<td>□ Yes □ No □ Not Applicable</td>
<td>□ Yes □ No □ Not Applicable</td>
</tr>
<tr>
<td>If pregnant, how far along in months?</td>
<td>□ 1-3 □ 4-6 □ 7-9 □ Not Applicable</td>
<td>□ 1-3 □ 4-6 □ 7-9 □ Not Applicable</td>
<td>□ 1-3 □ 4-6 □ 7-9 □ Not Applicable</td>
<td>□ 1-3 □ 4-6 □ 7-9 □ Not Applicable</td>
</tr>
<tr>
<td>If pregnant, are you (or a family member) seeing a doctor or nurse for this pregnancy?</td>
<td>□ Yes □ No □ Not Applicable</td>
<td>□ Yes □ No □ Not Applicable</td>
<td>□ Yes □ No □ Not Applicable</td>
<td>□ Yes □ No □ Not Applicable</td>
</tr>
<tr>
<td>What is the doctor or nurse’s name?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. If you (or a family member) are between the ages of 2 and 21, when did you last see a dentist?</td>
<td>less than 6 months ago 6-12 months ago 12 months or more</td>
<td>less than 6 months ago 6-12 months ago 12 months or more</td>
<td>less than 6 months ago 6-12 months ago 12 months or more</td>
<td>less than 6 months ago 6-12 months ago 12 months or more</td>
</tr>
<tr>
<td><strong>Circle the answer</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Case Study: Michigan

I. Background and Introduction

Medicaid eligibles in Michigan, including SSI recipients, have been required to enroll in some form of managed care since 1994. Within this system, two special provisions were originally made for children with special health care needs: SSI-eligible children were permitted to choose among the “physician sponsor plan” (PSP), a primary care case management model; a partially-capitated option known as the Clinic Plan; or a fully-capitated HMO. Most children on SSI enrolled in the PSP. Those who were eligible for the Title V Children’s Special Health Care Services (CSHCS) program were exempt from the managed care requirement, although they were permitted to enroll in the PSP if they chose.

Although state policy makers generally embraced managed care for Medicaid eligibles, state Title V and Medicaid officials were concerned that mainstream health plans were not designed to meet the complex needs of CSHCN, particularly those who qualified for the CSHCS program. However, they did believe that a managed care model, if designed correctly and overseen closely, could represent an improvement over the traditional fee-for-service system. Therefore, in 1995, state officials began developing a separate capitated program for children enrolled in CSHCS, whether or not they were eligible for Medicaid. The program development process was led by an interagency, multidisciplinary group that included not only Medicaid and Title V officials but also families of CSHCN, providers, managed care organizations, and advocacy groups. After considering alternative approaches, this body concluded that a specialized managed care model—one that took advantage of market forces but was guided by a detailed RFP—was the best way to reach the goal of a family-centered, culturally competent, community-based, coordinated system.

This program began implementation in six counties in September 1998. The program is voluntary; families are allowed to choose between a capitated HMO (known as a Special Health Plan) and the Fee-For-Service Plan. If they choose a Special Health Plan, they may enroll their
child in one of two plans, depending on their county. Children’s Choice of Michigan, which is run by the Detroit Medical Center, operates in Wayne, Oakland, and Macomb Counties, and Kids Care of Michigan, which is operated by the University of Michigan Health System and the Henry Ford Health System, is in these three counties as well as Washtenaw, Livingston, and Monroe counties. The two participating plans are beginning to expand beyond these six counties, and both participating plans expect to expand their services to all counties in the state within the next two years.

Michigan’s approach represents an example of a specialty managed care model targeted to children with special health care needs. To study this model more closely, researchers from the National Policy Center for Children with Special Health Care Needs conducted a 3-day site visit in February 1999. The site visitors interviewed state Medicaid and Title V officials, staff of both plans in Wayne County, and representatives of other systems that serve children, including the early intervention program, the special education system, and the state mental health agency. (A list of key informants is included in Appendix A.) This report presents details of Michigan’s model in Section II, focusing on how the model supports service integration. Section III discusses the lessons about service integration learned through this model.

II. The Model

The Michigan CSHCS program is administered within the Department of Community Health (DCH). This agency comprises the state Medicaid, public health, and mental health agencies. Within DCH, the Medical Services Administration (MSA) is responsible for both Medicaid and the CSHCS program. (The rest of Title V is housed in a separate Bureau within DCH).

CSHCS is responsible for all specialty care for qualifying children in Michigan. The eligibility criteria for CSHCS are expansive, covering more than 2,700 diagnoses. No income standard is used to determine eligibility; rather, family income is used to set a cost-sharing rate, with free care provided to children with family incomes below 200 percent of the federal poverty level. CSHCS provides specialty coverage only, and is the payer of last resort for covered services. Nearly half of enrollees have Medicaid coverage, and about one-third have private insurance.
The benefits available to CSHCS enrollees under the Special Health Plans depend on the child’s insurance status. The CSHCS program is coordinated with Medicaid and MI Child (the state’s Title XXI Child Health Insurance Program) through a system of “tracks,” as described below.

- **Track I** includes children who are eligible for CSHCS only, not Medicaid or MI Child. These children receive specialty care related to their qualifying diagnoses as well as well-child exams and immunizations. They may choose to receive services through either the Fee-For-Service Plan or the Special Health Plans; however, the preventive health care benefits are offered only if the child enrolls in a Special Health Plan.

- **Track II** includes children who are eligible for both CSHCS and Medicaid. These children are entitled to receive CSHCS specialty care as well as the full Medicaid and EPSDT benefit package. These children may choose between the Fee-For-Service Plan and the Special Health Plans.

- **Track III** includes MI Child enrollees who are also eligible for CSHCS, and who live in the six-county area in which the Special Health Plans operate. These children receive all of their services from CSHCS; however, they are not given the option to use the Fee-For-Service Plan. Because the MI Child legislation requires the program’s enrollees to use managed care plans, these children must choose a Special Health Plan for their care. These children receive a benefit package that is equal to that of the state employees’ health plan, with the addition of vision and dental services.

Whether enrollees choose the traditional Fee-For-Service delivery system or the Special Health Plans, CSHCS services are closely managed. The specific features of the Special Health Plan model, and how they differ from features common to the Fee-For-Service Plan and mainstream managed care are described in the following sections.

A. Eligibility, Identification, and Enrollment

The process of enrolling in CSHCS begins in one of two ways. Medical reports from pediatric subspecialists, hospitals, or other providers may be received by the State CSHCS program office; these reports are reviewed to determine if the child has a CSHCS qualifying diagnosis. Once this medical eligibility is determined by the State CSHCS program office, the family must complete an application for their child to join the CSHCS program. Alternatively, children may be referred to the CSHCS program by a local health department based on a referral from anyone
who suspects that the child may have a special need, including school nurses, social workers, primary care physicians, or families. If no reports are available from a medical specialist, the health department will refer the child to a local specialist for a diagnostic visit, for which the provider will be reimbursed by the CSHCS program. The medical report will be sent to the State CSHCS program office for a determination of medical eligibility. If a qualifying condition is identified, the family will complete an application to enroll their child in the program. In both cases, a financial review is conducted to determine the family’s level of cost-sharing, if any. To promote the identification of children, the Wayne County Health Department has sent out mailings to physicians’ offices and given presentations to community organizations; however, health department staff acknowledge that more outreach is needed to assure that all eligible children are identified.

Once enrolled in CSHCS, the child’s name is forwarded to the state’s enrollment contractor, Maximus (called “Michigan ENROLLS”). This agency is responsible for brokering managed care enrollment in all of the state’s public-sector insurance programs; however, the agency maintains a separate phone line and trained staff dedicated to the CSHCS program. For CSHCS, Michigan ENROLLS sends a packet of information to each family as they join or renew their eligibility for the CSHCS program. The packet informs them of their choices and describes the Fee-For-Service Plan and the two available Special Health Plans. If the family does not respond within ten days, Michigan ENROLLS staff will call the family, and after 15 days, a reminder letter is sent. After 20 days, if the family has still not made a choice, the staff will conduct a home visit, and after 30 days a final letter is sent. If no response is received after 45 days, the case is referred back to the state CSHCS program. Rather than being auto-assigned to a plan—a practice common to most managed care systems—new eligibles who do not make a plan choice lose their eligibility for CSHCS.

When talking to families about their options, Michigan ENROLLS staff explain the difference between the Fee-For-Service Plan and the Special Health Plans, and inform them which of the two plans include families’ providers in their networks. At present, approximately 35 percent of new enrollees choose one of the Special Health Plans rather than the Fee-For-Service Plan. At this writing, total enrollment in the Special Health Plans stood at less than 350 children. State
and local program staff report that the capitated plan option is still too unfamiliar to families, and most feel more comfortable in the Fee-For-Service Plan until the Special Health Plans have more experience treating children with complex needs.

B. Primary Care

Once enrolled in a Special Health Plan, the family is asked to choose a Principal Coordinating Physician (PCP) from the plan’s network. Both plans report great flexibility in who can fill this role; it may be a generalist pediatrician or a specialist, or two physicians can share the responsibility. Both plans require that the PCP not be a surgeon. The PCP is responsible for authorizing the child’s Individualized Health Care Plan (IHCP), which will be discussed further in the next section.

The guarantee of a primary care medical home and the availability of preventive care services through the Special Health Plans, especially for those children who are not eligible for Medicaid, were described as some of the major benefits of the capitated program over the Fee-For-Service Plan, which covers only specialty care related to the child’s qualifying diagnosis.

C. Specialty Care

The services authorized for each child are described in the child’s IHCP, which includes referrals for well-child exams and immunizations, subspecialty consultations, surgical care, rehabilitation services, oral medications, nursing needs (including respite care), medical equipment and supplies, behavioral services, dental care, non-emergency transportation, education, chiropractic services, and hospice care. Each plan uses its own form for development of the IHCP.

The IHCP is developed within 60 days of enrollment by the child’s community-based care coordinator and the family, and must be signed and agreed upon by the child’s PCP and the family. Once approved, this Plan serves as a “blanket” prior authorization document, relieving
both parents and providers of the need to obtain separate authorizations for each referral. This plan is revisited annually to ensure its ongoing appropriateness, although it may be changed at an interim point if a child’s needs change. The major reported advantage of the IHCP is that the provision of advance approval for all needed services allows care to be provided much more efficiently; waiting for approval for each service can be a major barrier to the receipt of timely care.

The networks of individual and institutional providers within each plan are extensive. The RFP required the development of comprehensive provider networks, including acute care hospitals, pediatric medical and surgical subspecialists, regional pediatric centers, hospitals with pediatric capacity, and other ancillary health professionals. In response to these requirements, new alliances were formed among the major providers of pediatric specialty care in the state. Henry Ford Health System collaborated with the University of Michigan to develop Kids Care, a new non-profit organization that takes advantage of the primary care capacity and culturally competent care offered through the Henry Ford Health System and the extensive specialty networks afforded by the University of Michigan Health System. Likewise, Detroit Medical Center formed Children’s Choice, a product that is in the process of becoming a separate licensed HMO. This system includes Detroit Children’s Hospital, more than one hundred outpatient clinics, and a home health service.

In addition to the providers and institutions in each plan’s networks, specialty services are provided through the 107 CSHCS-approved Children’s Multidisciplinary Specialty (CMS) clinics. These clinics are located throughout the state and provide comprehensive evaluations from a subspecialist, social worker, psychologist, nutritionist, and other providers as appropriate, based on the specific type of clinic.
D. Case Management

Two kinds of case management are provided within the Special Health Plan model. A local, or community-based, care coordinator is responsible for the development of the IHCP and for ongoing care coordination for the child and the family. Within each plan, plan-based care coordinators also perform a more traditional case management function, monitoring the receipt of authorized services and approving changes to the IHCP. The roles of these two case managers are described in more detail below.

- **Local care coordinator.** Each family chooses its local care coordinator from the agencies under contract with their plan in their county. These may include local health departments, CMS clinics, and home health agencies. Nurses within these agencies serve as care coordinators who generally monitor the child’s care through telephone contacts and letters to the family. No strict protocols govern these contacts; rather, the level and intensity of ongoing contacts depends on the needs of the family.

The care coordinator in the Wayne County Health Department, which provides care coordination for Kids Care enrollees, described this as a wide-ranging role, including medical services as well as educational, social service, and family support needs. However, staff shortages prevent the health department from providing extensive follow-up case management beyond the initial development of the IHCP.

- **Plan-based care coordinator.** The role of this care coordinator, in contrast to the local care coordinator, resembles that of a typical case manager within a managed care plan; that is, it is focused on reviewing and authorizing services and responding to questions. Nurses serve as care coordinators within each plan. These care coordinators are responsible for reviewing the IHCPs authorizing payments to the local care coordinators, training local care coordinators in developing IHCPs, and responding to questions from families about the plan or handling problems receiving services. The plan-based care coordinator is the first person to contact the family to identify the child’s immediate needs and to ascertain the family’s preference as to who should be the local care coordinator.

The two plans have different mechanisms for paying local care coordinators. Children’s Choice pays a flat rate of $200 per child per year, to cover the development of the IHCP and any
ongoing care coordination provided. Kids Care, by contrast, pays its care coordinators $150 for the development of the IHCP and $30 for each of two follow-up care coordination visits that are permitted each year.

Care coordination may be funded through two sources. When home health agencies or CMS clinics provide local care coordination, they are paid out of the plan’s capitated rate. As will be discussed later, plans may spend no more than 5 percent of their total capitation payments on care coordination. However, separate funding is available for paying local health departments to provide care coordination. A fund of $681,000 has been set aside for this purpose. Thus, the plans have a financial incentive to contract with local health departments to provide this service.

E. Family Involvement

The Michigan CSHCS program has a long history of involving parent consultants in the oversight of its programs and developing and supporting networks of families of CSHCN. (These efforts will be discussed in more detail in the next section.) In addition, families of CSHCN have been involved in the Special Health Plans program since its design phase, through their participation in the interagency groups that developed the system.

One of the major contributions of the parent consultants was the inclusion of the role of the Family Centered Care Coordinator within each plan. The role of these staff members, both of whom are parents of children with special health care needs, is to function at the policy and system levels to assure that the plans’ services are family-centered and to assure that the plan’s policies meet families’ needs. Examples of the activities of the two family-centered care coordinators include:

- Assuring that the plan’s written materials are clear and are written to respect the role of families in their children’s care;
- Training customer service staff to address families’ needs appropriately;
Revising the plan’s grievances and appeals process to be more family-friendly;

Educating individual families to identify their children’s needs and assure that these needs are met;

Participating in the plan’s utilization management program;

Training providers, school district staff, local health departments, and Michigan ENROLLS staff in the plan’s systems; and

Developing protocols for coordination with the early intervention program.

F. Links to Other Systems

As described above, the IHCP developed for each child enrolled in a Special Health Plan not only addresses children’s medical needs but may include information about services the child is to receive through the early intervention, special education, and mental health systems. While this holistic perspective is a strength, no clear mechanism appears to exist for coordinating and linking these outside systems. Specific arrangements between each of these systems and the Special Health Plans are described below.

- Early Intervention. Michigan’s early intervention program, known as Early On, serves children under age three who have either a documented developmental delay or a diagnosed condition that is likely to lead to a delay. Many of the children in the latter category are also eligible for CSHCS and, conversely, most children under age three in CSHCS are eligible for Early On. Therefore, children under three are automatically referred to Early On once they enroll in CSHCS. The development of the Individualized Family Service Plan (IFSP) is overseen by an Early On care coordinator chosen by the family. This care coordinator may be located in a local health department and could be the same person as the local care coordinator for the Special Health Plan, but the Early On program has no information about how often those roles overlap. The local Early On coordinator interviewed was also not certain how early intervention services for Medicaid-eligible children are financed or how medically necessary services are distinguished from those that promote development.

A workgroup within the state-level Part C Interagency Coordinating Council is considering how to better coordinate the Early On program with CSHCS, including the possibility of combining the IFSP and IHCP. Early On program
staff have also been meeting with the plans’ care coordinators to further explore how to develop a seamless system of care for their common enrollees.

- **Special Education.** The Michigan special education system, overseen through the state’s 57 Intermediate School Districts (ISD), serves children and adults from birth to age 26 and currently enrolls approximately 10 percent of schoolchildren who have developmental disabilities that affect their ability to learn. Once a child has been identified, evaluated, and enrolled in special education, an Individual Education Plan (IEP) is developed by an IEP Team comprising the parent, the teacher, the special education teacher, the school principal, and a representative of the ISD. A physician may be included in the team if necessary, but this is rare, and the school nurse may be on the team for medically fragile children.

If a child enrolled in Special Education is also enrolled in a Special Health Plan, the provider of special education services is supposed to share information with the child’s PCP. However, parents described themselves as their children’s primary case managers; coordination with CSHCS was not perceived as a role of the special education service provider.

School districts may bill Medicaid for medically necessary special education services provided to Medicaid eligibles. If these children are in a managed care plan, the school districts bill the state Medicaid agency directly, not the plan. Therefore, plans have an incentive to shift costs to the schools (and vice versa), and special effort must be made to assure coordination between the two systems. These systems are not yet in place, however, according to state officials; interagency agreements among the relevant state agencies are necessary to encourage this coordination on the local level.

- **Mental Health.** Responsibility for children’s mental health services under Medicaid is shared between the Special Health Plans and the state mental health agency. The Special Health Plans are responsible for up to 20 non-acute outpatient visits for children with mental health conditions. If children who require more than 20 visits have acute mental health needs, they are referred to the community mental health system. This may require that they change mental health providers.

The mental health carve-out is generally considered to be uncoordinated, particularly with the Medically Qualified Health Plans that serve the mainstream Medicaid population. State mental health officials are concerned that the plans may not make a genuine effort to assure that children are stabilized within 20 visits; rather, they have a financial incentive to refer to the mental health system immediately. Also, since plans are not responsible for paying for inpatient care, they have no incentive to try to avoid the need for psychiatric hospitalization. Finally, since the plans are responsible for prescription drug coverage, they are
required to pay for drugs that are prescribed by the community mental health system, which is considered to be inefficient.

The community mental health system also provides case management for its clients. This case manager develops a plan of care that focuses on assuring that the child and family have access to all the services they need to be able to keep the child at home. On the community level, the mental health system convenes “multipurpose collaborative bodies” to coordinate services and discuss policy and funding issues. These bodies include representatives of the school system, the courts, and the local health department, including the CSHCS program. These bodies generally do not address the coordination of services for individual children.

G. Financing

A critical element of the Special Health Plans model is its schedule of risk-adjusted capitation rates, based on age, children’s diagnosis, Medicaid eligibility status, insurance status, and geographic region. The development of this system was initially funded through a SPRANS grant from the Maternal and Child Health Bureau in 1994.

The risk-adjustment system was developed by the Boston-based Medicaid Working Group, and is a variation on that organization’s Disability Payment System. The central feature of the rate structure is the division of all qualifying diagnoses into four categories, based roughly on cost quartiles (with similar diagnoses assigned to the same category to avoid gaming). Within each of the four categories, separate rates are set for children enrolled in Medicaid and not; covered by third-party insurance and not; and within the Detroit metropolitan area and outside the metro area. In addition to the four diagnostic groups, separate rates are set for infants under age 1 and enrollees over age 20 within each of the coverage and geographic categories. A fifth rate category exists for children receiving hourly in-home nursing services. This category pays the highest monthly capitation rate per member and is not connected to diagnosis. Thus, the system includes a total of 49 rate cells.

The rates themselves were developed based on a database of CSHCS and Medicaid claims for eligible children for 1994 and 1995, then increased to account for cost inflation between the
The rates have since been further increased for inflation for 1998 and 1999, but have not been recalculated. The rate base also includes the cost of the full schedule of well-child visits recommended by the American Academy of Pediatrics for all enrollees.

Upon enrollment, plans are paid the appropriate rate for each child based on his or her diagnosis and other characteristics at enrollment, and are responsible for providing or arranging all of the child’s needed care with this capitation. However, the plans are protected from excessive losses by risk-sharing arrangements with the state, which include both stop-loss protection and risk corridors. The stop-loss provision requires that the state pay 90 percent of all expenses over $100,000 for any child per year of enrollment. The risk corridors require that the state and the plans share equally in losses if expenditures fall between 103 and 110 percent of the capitation payments, and require the state to absorb 90 percent of losses for payments above 110 percent of the rates. Conversely, the state retains all savings if payments are below 85 percent of the rates, and savings are shared equally if payments are between 85 and 92 percent of the rates.

The calculation of the plan’s annual expenditures includes two special provisions. First, only 10 percent of the final cost can be attributable to administrative costs (that is, the plans are required to report a medical loss ratio of no less than 90 percent); any additional administrative expenses must be absorbed by the plan. In addition, no more than 5 percent of expenditures can be attributable to care coordination. This figure was reported to be based on the average cost of case management in commercial managed care plans. (No explicit claims for case management or care coordination are included in the actuarial database on which the rates were based; however, since the CSHCS program has always provided some level of care coordination, the cost of this service is considered to be included in the rates.)

This program uses one of the few risk-adjustment mechanisms in existence that has been explicitly developed to compensate plans for the increased costs of treating children with special health care needs, and its system of diagnosis-based rates and risk-sharing provisions holds great promise. However, the plans and state officials expressed some concerns about these financing systems. First, the low administrative allocation may be inadequate, as plans have made considerable investments to develop their infrastructures, and the low levels of enrollment...
to date are unlikely to produce sufficient capitation payments to cover these costs. In addition, state officials recognize that the CSHCS fee-for-service delivery system was quite well managed, so the claims history on which the rates are based may leave little room for improved management and, thus, savings.

III. Directions for the Future and Lessons Learned Regarding Service Integration

Michigan’s system of managed care for children with special health care needs represents an innovative model, marked by close interagency and stakeholder collaboration and designed to address the needs of both families and plans as they provide care for CSHCN in a capitated system. However, the resulting Special Health Plans model was generally described as a “medical model” of managed care, and it does indeed focus on meeting enrollees’ primary and specialty medical needs without a clear system of coordination with systems of support services. This chapter will discuss the lessons that have been learned about service integration through the experience to date of Michigan’s Special Health Plans.

A. State-Level Coordination and Involvement of Title V

The CSHCS managed care program is unusual in that it represents a close collaboration between the state’s Title V and Medicaid agencies, along with outside agencies, including providers and consumers. This collaborative approach produced a model that defines the population of children with special health care needs more broadly than a program run only by Medicaid might. Indeed, DCH describes the system as inclusive of “all children with special health care needs,” not just those who are eligible for SSI.

In addition, interagency collaboration may have been strengthened by the reorganization of the Department of Community Health to encompass the two agencies. The reorganization is also reported to have promoted coordination between CSHCS and the community mental health system, although that relationship could still be strengthened significantly.
B. Identification and Enrollment

To date, a minority of families who are offered the choice between the Fee-For-Service Plan and the Special Health Plans have chosen to enroll their children in the capitated plans. These results are not a major concern for state officials, as they recognize that it will take time for people to feel comfortable choosing a managed care plan in a voluntary system. Enrollment can be expected to grow over time, as long as word of mouth about the program is positive. However, the small number of children enrolled poses a significant problem for the plans, who must absorb any administrative costs above 10 percent of the capitation payments they receive, and who have invested considerable amounts in developing their systems.

The total enrollment in the CSHCS program is approximately 28,000. The option to enroll in the Special Health Plans is currently only available in a limited number of counties and, while families may enroll at any time, the option is only explicitly offered to children as they enroll or renew their eligibility for CSHCS; therefore, the system is designed to enroll children in the program gradually. This may make it difficult for the plans to realize financial success, at least in the early years of the program.

State officials and local representatives differed in their perspectives on the success of the system used to enroll children in CSHCS. Some felt that it was important that an impartial agency oversee the decision between the managed care and fee-for-service systems, as local health departments may be tacitly steering clients to the Fee-For-Service Plan. Others did not see this as a problem (indeed, the CSHCS coordinator in the Wayne County Health Department preferred the capitated program), and felt that the use of Michigan ENROLLS posed an unnecessary step in the enrollment process, and that the local health departments were well-suited to managing enrollment.

C. Case Management
The opportunity to provide better management of care was widely reported to be one of the major advantages of the Special Health Plans option. However, it was not clear that the plans’ networks and financing systems supported intensive, ongoing, community-based care coordination. For example, one of the two plans does not pay its contractors for ongoing case management visits. Instead, the payment for the development of the IHCP is intended to function as a capitated rate for all case management services. No clear protocols appear to be in place governing the provision of case management, and several informants expressed doubts that home health agencies and CMS clinics were well-suited to providing comprehensive care coordination, including coordination of non-medical services.

A critical issue in the provision of care coordination by the Special Health Plans is that of how the service is financed. As described above, no explicit case management expenditures are included in the base for the state’s capitation rates, and the plans can attribute no more than 5 percent of their expenditures to care coordination. Thus, these omissions and limits convey a puzzling mixed message to the Special Health Plans regarding the emphasis they are to place on case management—while the state expects it to be a centerpiece of the plans, little direct financial support is extended to support this core function.

These mixed messages may be reinforced by Michigan’s decision to set aside some of the $681,000 earmarked for care coordination to provide an incentive for the Special Health Plans to use local health departments to perform case management for their enrollees. This structure suggests that state officials preferred to maintain this critical function apart from the responsibilities of health plans, and perhaps also that state and officials placed a high priority on preserving some role for local health departments in the new managed care system. Given this set-aside, plans now have a clear financial incentive to use the health departments for community-based care coordination; however, there is already evidence that the private plans may be resistant to this somewhat forced arrangement. For example, Children’s Choice does not contract with the Wayne County Health Department. Therefore, it remains to be seen if the financing and delivery arrangements for case management created by CSHCS are both efficient and effective.
In addition, there appears to be a plethora of case managers and care coordinators working with CSHCN in Michigan. As discussed above, the early intervention and mental health systems each support care coordinators, both of which have a broad responsibility to assure that the child’s and family’s needs are met. In some cases, these coordinators operate under strict protocols requiring visits at specific intervals. These visits were described as sometimes intrusive and unnecessary. Many families would prefer either to manage their children’s care themselves or to choose a primary coordinator from among the many who are responsible for their children’s care. This latter approach was endorsed by several state officials who understood the inefficiency of providing multiple case managers to some children while others may receive minimal ongoing case management from CSHCS.

D. System for Referral and Information-Sharing

The IHCP developed for each child was described as an effective, central document guiding referrals and authorizing services. The forms used by the two plans include sections to list support, educational, and other services that fall outside the plans’ responsibility. However, few explicit mechanisms appear to exist to assure that information is shared and children are referred between the plans and outside systems such as early intervention, mental health, and special education. Part of this deficit grows from the lack of a strong, centralized case management system, as described above. However, additional factors undermining effective information sharing are discussed below.
E. Financing and Shared Funding

As discussed in the previous chapter, the state’s system of risk-adjusted capitation rates helps to assure that the Special Health Plans receive sufficient funding to meet the needs of children with complex conditions. However, any capitated system offers an incentive to shift costs to other payers whenever possible. It is not clear that systems are in place in Michigan to coordinate the financing of medically necessary services that might be provided through other systems, such as mental health, special education, and early intervention. Funding issues with these three systems are discussed below.

- **Mental Health.** The carve-out of mental health services beyond 20 outpatient visits has been a consistent problem, according to Michigan officials and providers. The plans have an incentive to refer children to the community mental health system for intensive mental health services rather than providing outpatient visits under the plan. Moreover, if there is no contractual agreement between the Special Health Plans and the community mental health system, a referral from the plan to the mental health system may require children to change providers.

- **Early Intervention.** The local Early On councils were described as fairly autonomous, and they do not seem to have a consistent policy regarding how medically necessary early intervention services for Medicaid-eligible children are financed. This issue is currently being discussed by the state Interagency Coordinating Council.

- **Special Education.** For the past five years, school districts have been permitted to bill Medicaid directly for medically necessary services provided to Medicaid enrollees. Because these services are financed outside of capitation rates, plans have a clear incentive to refer as many education-related services as possible to the school districts, and the school system has had to resolve disputes about the educational necessity of referred services. (The ISDs’ guideline is that the schools are responsible for services to address ongoing disabilities that create an educational need.) Because these services are not financed by the plans, no obvious mechanism exists for the two agencies to communicate about services provided to common enrollees.

Although the state’s risk adjustment method demonstrates a level of sophistication that exceeds that of many other states, progress remains to be made in assuring that other financing sources
are maximized and the financing systems of the various programs that serve CSHCN are coordinated.

F. Family Involvement

Michigan has long been a leader in assuring family involvement in its CSHCS programs. Since 1988, the Parent Participation Program has worked to assure that systems of care for CSHCN are family-friendly. The program’s staff developed a manual for parents about the CSHCS program, and they review all of the program’s materials to assure that they will meet families’ needs. The program trains parents across the state to run support groups and provide one-on-one peer counseling; runs workshops and conferences for siblings of CSHCN to discuss family issues; and staffs a toll-free phone line that gives parents access to other parents, physicians, and local health departments.

The program has also been instrumental in the development and promotion of the Special Health Plans. Program staff helped to develop the original request for proposals from plans. Their contributions included the role of the family-centered care coordinator in each plan; the use of the IHCP as a standing referral for ongoing specialty services; and the requirement that consumers be included on the health plans’ governing boards and on the CSHCS program’s Advisory Committee. The inclusion of the family-centered care coordinator was described as particularly important, as it assures that the parent’s perspective is represented within the plan. Parent Participation Program staff are currently working to educate parents to call these coordinators when they have problems with their plans.

The Parent Participation Program was also closely involved in the conduct of consumer forums throughout the state to explain the new options within the CSHCS program. The program paid for transportation and child care for parents, and found that most of the participants were families who had not previously been involved in the Program’s activities. Program staff also trained the dedicated staff of Michigan ENROLLS on issues related to CSHCN.
Staff of the Parent Participation Program are committed to educating families about the Special Health Plans and making the managed care program work. They see the major advantage of the managed care option to be the greater potential for care coordination, improved access to primary care, and access to a single resource for referrals and authorization.

G. Quality Assurance

Quality assurance and monitoring for the Special Health Plans is overseen by the Department’s Quality Systems Section within the Division of Managed Care Quality Assessment and Improvement. This section is responsible for monitoring the quality of all of the state’s Medicaid managed care programs, MI Child, and the behavioral health carve-out.

The section’s overall strategy for monitoring the quality of the CSHCS plans includes the following elements:

- A consumer survey, using the version of the Consumer Assessment of Health Plans Survey (CAHPS) instrument designed for children with special health care needs;
- Clinical measures using the Health Plan Employer Data and Information Set (HEDIS); and
- An external review, including a review of 200 medical records and administrative data from the plans, conducted by nurses with experience serving CSHCN. This review will allow for the examination of indicators specific to CSHCN, such as:
  
  Did the child receive the services listed on the treatment plan?
  
  Were all necessary providers involved in the development of the treatment plan?
  
  Was the level of inpatient use appropriate for the condition? Did the child use an appropriate level of inpatient care for problems unrelated to the qualifying condition?
  
  Did the child receive community-based care for routine health problems?
These indicators will also be examined for children enrolled in the CSHCS Fee-For-Service Plan in order to compare the process of care provided in the two delivery systems. All of these efforts will be conducted by outside contractors, and requests for proposals have been issued to identify these organizations. The CSHCS program will also conduct targeted consumer satisfaction surveys on specific topics related to the Special Health Plans and the Fee-For-Service Plan.

This strategy is commendable, as it is both consistent with mechanisms used to assess the quality of mainstream Medicaid managed care programs and tailored to monitor plans’ ability to meet the specific needs of CSHCN. However, it has a significant gap. While most of the plan representatives and state officials interviewed reported that the Special Health Plans approach was preferable to fee-for-service because of the care coordination it provides, the quality monitoring plan does not yet include an effort to measure or monitor the effect of this coordination. Without indicators that reflect the process and outcome of care coordination, it will be impossible to determine whether the capitated program fulfilled its promise in this area.

In conclusion, Michigan appears to have developed a sophisticated model for meeting the medical needs of CSHCN and for compensating managed care plans appropriately in a capitated system. As mentioned above, the Michigan model is a specialty managed care system, and as such it includes several features not commonly found in mainstream Medicaid managed care systems. These include:

- An emphasis on community-based care coordination;
- The use of a care plan that includes authorization for all specialty and ancillary services for a full year;
- Inclusion of a family perspective in both the implementation and oversight of the system;
- Risk-adjusted capitation rates that are tied to a child’s diagnosis; and
- A quality monitoring system that includes measures specific to CSHCN.
This structure shows significant promise as a model for the provision of medical care to CSHCN in a managed care environment. As implementation of this system continues, state officials will confront the challenge of addressing the unanticipated gaps in the system, particularly the coordination of these medical services with the range of educational and support services these children need. The state’s history of using a multidisciplinary, interagency approach to program planning puts it in an excellent position to face these challenges.
Appendix A: Key Informants

The following persons were interviewed by researchers of the National Policy Center for Children with Special Health Care Needs in their study of Michigan’s specialized managed care network for CSHCN:

<table>
<thead>
<tr>
<th>Michigan Department of Community Health</th>
<th>Children’s Choice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jane Finn</td>
<td>Herman Gray</td>
</tr>
<tr>
<td>Karla Marsh</td>
<td>Angela Lee</td>
</tr>
<tr>
<td>Denise Holmes</td>
<td>Angela Patterson</td>
</tr>
<tr>
<td>Robert Smedes</td>
<td>Terri Wheeler</td>
</tr>
<tr>
<td>Stephen Fitton</td>
<td>Liz Kent</td>
</tr>
<tr>
<td>Neil Oppenheimer</td>
<td>Vernal Reeves</td>
</tr>
<tr>
<td>Lori Irish</td>
<td>Beverly Crider</td>
</tr>
<tr>
<td>Debbie Milhouse-Slaine</td>
<td></td>
</tr>
<tr>
<td>Mary Marin</td>
<td></td>
</tr>
<tr>
<td>Julie Griffith</td>
<td></td>
</tr>
<tr>
<td>Lisa Cook-Gordon</td>
<td></td>
</tr>
</tbody>
</table>

Michigan Department of Education

James Paris

Michigan ENROLLS

Rebecca Start
Terri Reed

Wayne County Health Department

Betty McCoy

Kids Care

Laura Eory
Nora Lessnau
Bev Nugent
Case Study: Minnesota

I. Background and Introduction

In 1985, Minnesota began implementing its Medicaid managed care program, the Prepaid Medical Assistance Program (PMAP), in three counties. This program, which provides the full Medicaid benefit package through fully capitated managed care plans, has gradually expanded over the years and now operates in 53 of the state’s 87 counties. However, Medicaid eligibles enrolled in Social Security Income (SSI) and children with disabilities needing home- and community-based services covered under the Tax Equity and Fiscal Responsibility Act (TEFRA) are exempt from enrolling in managed care.

Minnesota officials have been planning for several years to integrate children on SSI into the PMAP system. Only now, however, are Medicaid managed care programs for people with disabilities being designed, and only in four areas. Two pilot projects, known as the Minnesota Demonstration Projects for People with Disabilities, or the “disability pilots,” are being developed in Olmsted County and in a three-county area including Blue Earth, Freeborn, and Sibley Counties, known as the Southern Minnesota Health Initiative. In addition, two other pilot counties are in the planning stages: Hennepin County (which includes Minneapolis) and Itasca County. The pilot projects will provide all Medicaid-covered acute and long-term care benefits on a fully-capitated basis, and services will be delivered through existing managed care systems. These systems are being designed on the local level through lengthy, intensive interagency planning processes that involve coordinated planning and integrated funding. Implementation in the two original demonstration sites is planned for early 2000.

Minnesota was selected for this study to represent a model in which children with special health care needs are currently excluded, or “carved out,” from managed care arrangements. Thus, the state was seen as a point of comparison against which states that enrolled CSHCN in managed care systems could be assessed. A site visit was not conducted; instead, interviews were conducted by phone. Our informants included several representatives of the Minnesota
Departments of Human Services, Health, and Children, Families, and Learning; representatives of one managed care plan, one children’s hospital, and one of the two pilot projects; one individual provider; and one family advocate.

In gathering information about the system of care that serves CSHCN in Minnesota, it became clear that three models of care are in place or in development in the state: the fee-for-service system that serves children on SSI or TEFRA; the PMAP program that serves children on Medicaid, including those CSHCN who are not eligible for SSI; and the pilot projects, which are under development for children (and adults) with disabilities who are excluded from PMAP. Therefore, this report will address the provisions of all three of these systems and assess their abilities to provide integrated services.

The next section of this report describes in detail the three models of care currently in place or under development to serve children with special health care needs in Minnesota under the state’s Medicaid program. Specifically, this chapter will review the mechanisms that are used to identify CSHCN in these systems, their systems for providing of primary and specialty care, the structures in place for providing case management services, and the manner and extent to which services are integrated across systems under each of the three programs. The third section of the report summarizes the lessons that state officials and providers have learned from the continued evolution of Medicaid managed care in Minnesota and their implications for service integration.

II. The Models

As discussed above, three Medicaid models are in place or in development in Minnesota:

- **Fee-for-service Medical Assistance.** A traditional fee-for-service Medicaid system serves children with disabilities who fall into one of four categories:
  - Those eligible for SSI;
– Those on the TEFRA program, which provides wraparound Medical Assistance coverage of home-based services for children with severe disabilities who would otherwise be candidates for institutional care;

– Children determined by a State Medical Review Team (SMRT) to be exempt from managed care; and

– Children with serious emotional disturbances (SED), who are being case-managed, and who have a provider who is not in a managed care network.

According to officials interviewed for this study, the decision to exclude CSHCN from capitated managed care arrangements was based not on concerns that these children would receive poor quality care from managed care plans, but over concerns that the local agencies and providers who traditionally serve them could not remain fiscally viable in an environment in which they were required to subcontract with managed care plans. Therefore, these children were excluded from PMAP until a system could be designed that met the needs of these providers as well as those of the enrollees.

The Prepaid Medical Assistance Program (PMAP). PMAP, Minnesota’s fully capitated Medicaid managed care program, currently covers 53 of the state’s 87 counties. This program enrolls 70 percent of all Medicaid-enrolled individuals eligible for enrollment in managed care. The exclusions listed above are intended to assure that CSHCN are not enrolled in capitated managed care inappropriately; however, some children with chronic conditions do not meet any of these criteria and are therefore enrolled in PMAP. In particular, if families choose to enroll in Temporary Assistance for Needy Families, rather than SSI, because benefit levels are higher, their children will be enrolled in PMAP. In addition, children who lost SSI after the eligibility standards changed with the passage of the Federal Personal Responsibility and Work Opportunity Reconciliation Act may be enrolled in PMAP. Finally, of course, children whose disabilities do not qualify them for SSI or TEFRA, who do not have SED, and who do not meet the SMRT criteria will be enrolled in PMAP as well.

Minnesota Demonstration Project for People with Disabilities. As described above, these demonstration projects will provide the full range of Medicaid services for eligibles with disabilities under age 65, including children on SSI, children with SED, and children with mental retardation or related conditions. The pilots are to be designed by local work groups including consumers, family members, and providers, and are to include an extensive service coordination component; this will be discussed in detail below. The pilot projects are to begin enrollment in early 2000.
The following sections will describe critical aspects of each of these three service delivery systems, focusing on models of service integration that are emerging as these systems evolve.

A. Eligibility, Identification, and Enrollment

A critical element of a system of care for CSHCN is the ability of that system to identify these children, assure that they are assigned to providers who are trained and experienced in caring for children with complex needs, and to assure that their needs are identified and met. Without a mechanism for systematically identifying CSHCN and assessing their needs, children may be enrolled in managed care systems inappropriately, may not receive comprehensive case management, and may not receive family support services for which they are eligible. The provisions for identifying CSHCN and enrolling them with appropriate providers in Minnesota’s three systems exemplify the evolution of the state’s Medicaid program in addressing the needs of CSHCN.

- **Fee-for-service Medical Assistance.** In the fee-for-service system, Medicaid eligibles are free to choose any available provider who will accept Medicaid. The state Department of Human Services does not provide any assistance in finding or choosing providers or any information on available providers who are skilled in serving CSHCN. The state’s Title V Children with Special Health Care Needs program can provide such assistance to children, particularly those on SSI, with whom they have contact, but not all such children are involved in the Title V program. Thus, no systematic mechanism exists to identify CSHCN and assure that they receive a comprehensive service plan under the fee-for-service system.

- **PMAP.** People can enroll in PMAP through two main avenues: the county welfare system or the MinnesotaCare program (the state’s public-sector insurance program for uninsured Minnesotans, including children and families with incomes above the traditional Medicaid eligibility standard). Those who use the county system meet with an “enrollment manager” at the county social services office, who can provide information about the available plans and help families to choose a plan that includes familiar providers. The MinnesotaCare program, which serves families at higher income levels, also uses the PMAP network of managed care organizations. Families enroll in this system through the mail, and all enrollment processing functions are conducted at the state level. No in-person help is provided in choosing a plan. Although information about
the available plans is included in the enrollment materials, state officials have found that approximately one-fourth of MinnesotaCare enrollees are assigned to a managed care plan because they do not voluntarily choose one.

The PMAP plans do not have a systematic method for identifying CSHCN enrolled either through Medicaid or through their commercial contracts. One plan has conducted retrospective analyses of the service utilization and expenditures of children with a selected group of diagnoses; however, this strategy has not yet been used to identify children prospectively for the purpose of enhancing service delivery.

- **Disability pilots.** Since all enrollees in the pilot projects will have disabilities or chronic conditions, these programs do not need to have a system to identify CSHCN. However, a process is needed to assure that enrollees choose providers who are qualified to provide the care they need. The disability pilot projects are more likely than the PMAP plans to provide in-depth orientation to enrollees and guidance in choosing providers. In Olmsted County, the enrollment process will include a home visit at intake during which intake workers (from the county public health or social services agency) will explain the program, perhaps show a video explaining the managed care program, answer questions, and help the enrollee to select a provider.

Thus, in developing the pilots, state officials appear to have recognized the need for systems to assure that CSHCN receive appropriate care, systems that do not exist in either of the other two Medicaid models in place in the state.

**B. Primary Care**

Although much of the focus for CSHCN is on the provision of specialty care and ancillary therapies, access to primary care through a consistent medical home is as essential for these children as it is for any other children. Under the fee-for-service Medicaid system, CSHCN’s access to providers of primary care, particularly those who are trained in and comfortable with the care of children with complex needs, has never been monitored. State officials reported that access to EPSDT services under the fee-for-service system is, at best, equal to that available under PMAP. One area in which access problems have been documented is dental care; especially in rural areas, few dentists are willing to accept Medicaid and fewer are comfortable serving CSHCN. The fee-for-service system offers no guarantee that CSHCN will have a
primary care medical home; in fact, it is possible that the lack of appropriately trained providers and families’ focus on specialty care may mean that these children are unlikely to receive adequate primary care.

For children who are enrolled in the capitated system, access to primary care is, in theory, assured. Managed care models are typically constructed around the principle that all enrollees are provided with a primary care physician. Indeed, this theory is enforced in Minnesota through the EPSDT provisions in the state’s contract with managed care plans. However, although the PMAP contract encompasses the full EPSDT package and screening schedule, it is reported that plans use their own periodicity schedules for primary care and apply them to all of their enrollees, whether they are enrolled under PMAP or through commercial plans. To better monitor and enforce the PMAP contract’s primary care provisions, state officials are developing a new reporting form and revised requirements for the provision of EPSDT services.

The arrangements for the provision of primary care in the pilot projects are less clear. In Olmsted County, the county itself will act as the managed care plan and will accept risk; an administrative services organization will be engaged to process claims and provide a complete specialty care network. The full EPSDT benefit package will be provided, although Olmsted County’s plans for delivering primary care services are not yet complete.

C. Specialty Care

Access to a broad range of specialty services and ancillary therapies, from hospital care to physical therapy to supplies, is essential to providing appropriate care, promoting development, and supporting the functioning of CSHCN. In the fee-for-service system, however, DHS has little control over variations in practice and cannot assure access to needed specialty services. State officials report that since the number of children enrolled in SSI and TEFRA is low, Medicaid’s payment rates do not pose a major barrier to access to services; no one provider would see enough of these children for payment rates to present a major problem. A more significant barrier may be the state’s policies regarding access to services such as therapies.
Prior authorization is required for the receipt of physical, occupational, or speech therapy over certain limits, and the most frequent appeals of denials of service concern these therapies, as well as home care and durable medical equipment. This report was confirmed by providers, who report problems with DHS authorization of innovative devices and therapies, equipment, speech therapy, and treatment for feeding problems. Thus, use of a fee-for-service system does not guarantee easier access to specialty care.

Key informants reported problems with access to specialty care under PMAP as well. First, the introduction of PMAP may have disrupted the traditional referral patterns for some families. Services are still available to PMAP enrollees from Title V specialty clinics (which may then bill Medicaid or other insurers directly), but plans rarely refer their enrollees to these clinics. A second problem is the adequacy of plans’ specialty networks: plans do not necessarily include the full complement of pediatric subspecialists in their networks, perhaps on the assumption that children with complex specialty needs will not be enrolled in Medicaid managed care. Finally, plans are reported to use definitions of medical necessity that do not necessarily provide the breadth of coverage assured by EPSDT. Rather than apply different definitions to their commercial and Medicaid populations, plans use a single definition for all children, resulting in inappropriate denials of services such as speech therapy, home care, and durable medical equipment.

In contrast to PMAP, the pilot projects were specifically designed to assure access to comprehensive, coordinated services to people with disabilities. Therefore, the pilots have extensive provisions to assure access to specialty care and specialized therapies. In Olmsted County, coordinators plan to include the full Medicaid benefit package, as well as any community-based services that enrollees need. This is intended to include alternative therapies (such as, for example, equine therapy) that may help to support the habilitation or rehabilitation of enrollees. The plan’s coordinators are unsure how long-term care, particularly residential services, will be financed under the plan, and what level of long-term care meets the definition of medical necessity outlined in the state’s Medicaid State Plan.
D. Mental Health Services

Special mention should be made of Minnesota’s systems of mental health services for children, which are overseen on the county level. Minnesota has a well-thought-out system of mental health services for children. Children identified by a health professional as having SED (defined as a mental health condition and a functional impairment) receive case management through the county or its contractor. This case manager provides targeted case management, overseeing the child’s medical, social, and educational needs and coordinating between the county and the plan. Mental health treatment services are provided by PMAP plans (or their subcontractors), as part of the Medicaid benefit package.

Thirty-one counties have chosen to participate in 22 Children’s Mental Health Collaboratives (CMHCs), each of which includes representatives of the county, the school system, the correctional system, the local health department, and the mental health agency. These collaboratives serve children with SED who are not eligible for PMAP, receiving capitated payments from the state and sharing other sources of funding across systems. Nearly two-thirds of children in Minnesota live in counties that participate in CMHCs.

The CMHCs provide at least the full Medicaid package of mental health services, including day treatment, therapeutic foster care, and home-based services, but may also include other services that Medicaid does not cover. These often include respite care, family counseling, camps, and other wraparound services. These extra services are financed through the shared funding of the participating agencies. Case management in the CMHCs is provided by “wraparound coordinators” who work to coordinate all of the needs of the child and family. This role can be played by anyone of the family’s choosing, including a family member.

For children who are enrolled in PMAP, mental health services are part of the benefit package provided by the health plans. Plans may subcontract with the CMHCs in their counties for mental health services for children, but these arrangements are not common. When a provider in a PMAP plan identifies a child as having SED, the child is referred to the county mental
health system for case management; this service is reimbursed by DHS on a fee-for-service basis. The case manager then acts as a broker between the county mental health system and the plan, identifying the child’s needs, facilitating access to services, and making recommendations to the plan. This relationship is necessarily complex, as the case manager is responsible for referring children to services for which the plan is fiscally responsible. The ability of the case managers and the plans to coordinate effectively varies by county.

E. Case Management

Case management is a critical element of a system of care for CSHCN, due to the wide range of services these children and their families may need. Comprehensive assessment of a child’s needs, development of a care plan, referral to services, monitoring and coordination of services are essential elements of a case management service for CSHCN. No explicit case management benefit is provided for CSHCN in the fee-for-service Medicaid program, and no targeted case management service is covered for these children under the Medicaid state plan. However, although the fee-for-service system offers no systematic case management service to children on SSI or TEFRA, they may receive case management from their providers or through other systems. Examples of case management services offered by individual providers or institutions in Minnesota include:

- Gillette Children’s Hospital in St. Paul currently provides two forms of case management, and is considering developing a third, intermediate level. Currently, families who have the skills and capacities to navigate systems on their own can turn to the hospital’s Resource Center for information and resources to help them care for their children. Families with more intensive needs can receive support from a social worker, who can provide counseling and help the family to find and use community-based resources. Under development is a “care coordination” function which would assess the needs of children and their families; develop a family support plan; and train the parents to advocate for their children’s needs and use the health care and social service systems available to them.

- An individual primary care pediatrician, who cares for many children on TEFRA, has hired a Nurse Coordinator for children with special health care needs in his practice. This coordinator primarily handles insurance issues for these children,
which can be complex. She also works closely with hospital staff to arrange services for ventilator-dependent children.

- County social services departments provide case management for children with developmental delays or SED and targeted case management for children involved with the child welfare system. The scope of these case managers includes providing referrals and case management over the phone, focusing mainly on children’s mental health needs.

The PMAP contract includes language requiring plans to provide case management that is “designed to coordinate the provision of services to its enrollees and...promote and assure service accessibility, attention to individual needs, continuity of care, comprehensive and coordinated service delivery, and the provision of culturally appropriate care and fiscal and professional accountability.” Nonetheless, many informants reported that health plans did not provide comprehensive case management to their PMAP enrollees; rather, their case managers serve a more narrow function, focusing mainly on fiscal management and utilization review and are not well connected with community resources. This phenomenon is commonly observed in commercial managed care systems.

One plan has made an effort to identify CSHCN in both its Medicaid and commercial populations and to work with other community agencies that serve these children to develop a comprehensive, coordinated system of care to meet their needs. This project, known as “Brave New Partnerships,” involved HealthPartners, the Center for Children with Chronic Illness and Disability at the University of Minnesota, and the PACER Center. The project first conducted an assessment of the needs of children with chronic illnesses and disabilities. Phase II of the project involves the development of a case management system for CSHCN outside of the managed care plan. Funding is being sought to designate a case manager to work through the Early Intervention system to coordinate medical and social services for families of children enrolled in both Early Intervention and HealthPartners.

The pilot projects include an extensive case management service. The statute calls this function “service coordination,” to distinguish it from the type of case management typically provided by managed care plans, and includes a specific list of required activities, including the following:
Arranging for an initial assessment of supports and services based on the enrollee’s strengths, needs, choices, and preferences;

Arranging for and coordinating the provisions of supports and services;

Monitoring the progress toward achieving the enrollee’s outcomes in order to evaluate and adjust the timeliness and adequacy of the personal support plan;

Facilitating meetings and collaborating with a variety of agencies; and

Informing, educating, and assisting enrollees in identifying available service providers and accessing needed resources and services beyond the limitations of the medical assistance benefit set covered services (Demonstration Project for Persons with Disabilities statute).

The service coordinator will not be an employee of the county or the plan; rather, an enrollee’s family can choose anyone to act as a service coordinator, including a family member, who will be reimbursed for time and expenses. The service coordinator must be certified by the Administrative Services Organization hired to manage the program.

This model of care coordination, which is likely to include home visits, is intended to replace the various county-based case managers who currently serve SED and developmentally delayed children. It was designed specifically to meet the wide range of needs of people with disabilities and their families and therefore is far broader in scope than the case management function implemented in PMAP.

These three models illustrate the evolution of case management for CSHCN in Minnesota. Although the fee-for-service system does not provide a case management benefit, several individual providers and institutions have recognized the need to coordinate the care received by their pediatric patients, and have begun to independently develop case management systems. Similarly, the case management services generally offered by managed care plans under PMAP are generally recognized to be inadequate. Therefore, at least one managed care plan has begun to develop a more comprehensive case management model. Finally, the disability pilots appear to have been designed with the awareness that a comprehensive care coordination benefit is a necessary element of a system of care for people with disabilities.
F. Links Among Systems

As is evident from the above discussion, the fee-for-service “system” that serves many children with special health care needs in the Minnesota Medicaid program is not a system at all; rather, it is an insurance arrangement that simply permits eligibles to shop for care among participating providers and that pays those providers who accept its rates. Coordination with other systems, such as special education, early intervention, and mental health, is unpredictable.

Although PMAP was not intended to serve CSHCN, its contracted plans are expected to coordinate their services with these other systems, generally through their case managers. The case management mechanisms used in these programs and the systems for coordination with PMAP are described below.

- **Part C Early Intervention.** The Part C program provides early intervention services for children from birth to age three with a diagnosed developmental delay; children at risk of delay are not covered. Ten to 20 percent of children served by the program are eligible for Medicaid. Children receiving Part C receive case management from service coordinators, who work to coordinate the various agencies involved in the development of the child’s Individual Family Service Plan (IFSP). The service coordinators are also expected to refer clients to other needed services.

  Medicaid covers both medically and educationally necessary services under both the fee-for-service program and through PMAP, so all early intervention services should be covered by Medicaid. However, relations between the Part C service coordinators and PMAP case managers are not always cooperative; state officials report that the family must request that the plan reimburse for Part C services, and that families are left with the task of assuring that the plans pay for medically necessary IFSP services. DHS officials noted that a physician’s signature is not required on the IFSP; such a requirement might facilitate payment by health plans.

- **Special Education.** Special education is overseen by the Department of Children, Families, and Learning (DCFL) and is provided to children with physical, emotional, sensory, or cognitive disabilities that affect their educational performance. Services are provided based on an Individualized Education Plan (IEP) developed by a team including the teacher, the special education teacher, the child (if appropriate), a school administrator, the family, and a provider of other, related services (such as vocational rehabilitation), but not necessarily
including a physician. (DHS officials would like to require that the IEP be authorized by a physician, but the issue of whether the physician can override the decisions made by the other IEP team members has not been resolved.)

Schools may become Medicaid providers and bill the program for health-related special education services, but the required training discourages many school districts from doing so. To facilitate this process, DHS has created a new billing category called “IEP services” and a provider category called “IEP provider” to help schools to qualify more easily. As an added incentive, new legislation requires schools to bill all payers for special education services; no legislation requires commercial insurance to pay for these services, but Medicaid is required to do so. In addition, a new provision has been added to the PMAP contract requiring plans to work with schools and pay for health-related services.

Two additional areas where coordination can be improved are referrals and participation in the development of the IEP. According to DCFL officials, health care providers do not regularly refer children to special education; that is, EPSDT screens do not routinely lead to referrals. To improve coordination with plans, DCFL intends to begin inviting the plans’ case managers to IEP meetings. It is hoped that this will help to establish the relationships that can better support ongoing coordination and collaboration.

- **Mental health.** As described above, the county mental health system offers case management to children with SED. This case manager acts as a broker, facilitating access to services and making recommendations to the health plan about services that are needed. The success of this arrangement, in which care is coordinated for managed care enrollees by a case manager who is not employed by the plan, was described as variable, depending on the relationships between case managers and the health plans within each county. Some mental health providers report that children may not receive the services they need under this arrangement, or that plans attempt to shift costs to the counties.

The pilot projects are specifically designed to integrate the various systems that serve CSHCN. The projects are being designed on the local level by collaboratives of stakeholders from across systems, and a Children’s Issues Work Group was formed at the state level to discuss care coordination, contract standards, and systems for integration with schools and early intervention services. Moreover, the fiscal structure of the pilots is based on integrating funding across systems, including local sources of funding for people with developmental disabilities and mental health conditions as well as Medicaid funds. At this time, it remains to be seen whether the pilots will succeed in achieving these ambitious goals, however coordination mechanisms are being developed that promise to improve the health system’s integration with the early
intervention, special education, and mental health systems; for example, the program’s case managers will be invited to IEP meetings.

III. Directions for the Future and Lessons Learned Regarding Service Integration

Since the state began developing its Medicaid managed care systems, Minnesota has been careful and deliberative, phasing PMAP in gradually across the state to assure that managed care was not imposed before county systems were ready. Likewise, the extension of managed care to people with disabilities has been a protracted process. The state has been planning for the inclusion of SSI eligibles in PMAP since the early-1990s, and the process of developing the pilot projects has taken at least a year. According to key informants interviewed for this study, this pace has helped to assure that the systems that are eventually developed will have been considered carefully and will address the varied needs of this population.

The wisdom of such a deliberative approach depends on the quality of the Medicaid fee-for-service system that serves CSHCN during the long wait for the extension of the managed care system. In Minnesota’s case, according to some state officials, the exclusion of people with disabilities was not primarily intended to protect them from the risks of managed care; rather, concern for the viability of the providers who served these populations was the major consideration driving the policy. Thus, no attempt was made, nor has ever been made, to assure that the Medicaid fee-for-service system provided the protections CSHCN need, such as access to a medical home and a full range of specialty providers, case management, ancillary therapies, support services, and coordination among the various systems from which they receive services.

The case of PMAP is somewhat different. This system was not designed to meet the needs of people with disabilities, primarily because SSI eligibles have always been excluded from enrollment. Therefore, the PMAP system includes few provisions regarding the benefits, providers, and protections they need. It has become apparent that, despite the SSI exclusion,
some children with chronic conditions do enroll in PMAP, and their families are finding that this system is not designed to meet their needs.

The pilot projects offer great promise for the provision and coordination of care for Medicaid eligibles with disabilities in Minnesota. However, because the pilots will serve both children and adults with disabilities, some state officials have expressed concern that children with special health care needs will not be adequately served in these systems, as they will represent only a small proportion of the programs’ enrollees. Close monitoring of the pilots’ progress will be needed, not only to assure that appropriate services are provided to children but also to compare the process and outcomes of care provided in counties that are implementing different systems of care. It is not yet clear how monitoring and evaluation systems will be designed that are specific to the care of children.

On the state level, agency representatives and other stakeholders concerned with the attention to children in the design of the pilot projects convened a Children’s Work Group to provide recommendations for the program. This group, which included representatives of MDH, DHS, and DCFL; several plans, hospitals, and physicians; the pilot counties; and parents, considered such issues as care coordination, best practices, levels of care, and collaboration with the schools. The group developed a set of “Guiding Values and Principles for Serving Children with Special Health Care Needs,” which was distributed to all of the pilot counties and is available to the rest of the state’s 87 counties upon request. This document summarizes the major issues involved in serving CSHCN, describes the requirements of EPSDT, and includes the American Academy of Pediatrics’ definition of a medical home.

On the local level, several programs and systems have inspired groups of providers, consumers, and other stakeholders to work together to improve systems of care for CSHCN. Examples of local-level coordination in Minnesota include the following:

- Several individual providers and plans are working independently to design and test models of service coordination. These include the efforts of Gillette Children’s Hospital to develop alternative models of care coordination for its
patients, depending on the family’s needs, and HealthPartners’ work with the Early Intervention program to coordinate services for common clients.

- Through their mental health collaboratives, several counties are working to develop comprehensive, coordinated, integrated systems of mental health services, based on the sharing of funds across agencies.

- The disability pilots appear to be replicating that model for a broader population, with their efforts to develop systems that address the common needs of people with disabilities (rather than categorizing them by diagnosis) and that will integrate acute and long-term care and coordinate the range of services that enrollees use.

However, problems with service integration and coordination are still reported by a number of informants. Specific issues mentioned include the following:

- Coordination between health care providers and school districts is almost universally lacking. Although schools are required to bill health insurers (including Medicaid) for special education services, many still do not, and health care providers do not routinely refer children with disabilities to special education programs. Some plans are making efforts to improve coordination between these two important systems, but no systemic effort has yet been made in this area.

- The specialty managed care systems for people with disabilities being developed through the pilots will affect only those Medicaid enrollees who are eligible for SSI or are otherwise excluded from PMAP. No system-wide effort has been made to assure the appropriateness and quality of care provided to CSHCN who, for various reasons, may be enrolled in PMAP. Plans do not generally have methods of identifying these children, and case management is reported to be focused on fiscal concerns and utilization review rather than on care coordination. Thus, all of the effort by state and local agencies and stakeholders to design and implement comprehensive, coordinated systems of care for CSHCN may not benefit those children who are already enrolled in the state’s mainstream Medicaid managed care program.

- State and local officials, providers, and families have gone to great lengths to plan systems of care, in both the mental and physical health arenas, that are coordinated and integrated to meet the various needs of CSHCN and their families. However, despite these efforts, informants expressed dissatisfaction with various elements of these systems, including coordination between schools and health care services, the ability of health plans to provide comprehensive care coordination, and the difficulty of coordination among the various systems
that serve children. Thus, many participants in the system are concerned that the reality does not measure up to the scope and ideals of the state’s plans.

Minnesota’s model, therefore, is something of a paradox. Many informants agreed that the state’s devotion to careful planning and gradual implementation has served children well, as children have not been rushed into a managed care system that is not prepared to meet their needs. Another reported advantage of Minnesota’s approach is that it has allowed local communities to design systems, through the mental health collaboratives and the disability pilots, to meet their individual needs rather than mandating a single statewide approach.

This strategy, however, has promoted the development of a number of mini-systems, such as the mental health collaboratives, which must then be coordinated with the other systems that surround them. As one informant put it, “any time there is a split—of services, people, or dollars—you need to find a way to manage it.” Thus, the mental health collaboratives must coordinate with managed care, and individual case management programs developed by providers and plans must find a way to coordinate their efforts. Thus, although the theoretical model on which Minnesota’s systems are based shows great promise, much work remains to be done to assure that these new systems fulfill their promise as they are implemented.
Appendix A: Key Informants
Appendix A: Key Informant List

The following persons were interviewed by researchers of the National Policy Center for Children with Special Health Care Needs in their study of Minnesota’s systems of care for CSHCN:

Minnesota Department of Human Services
   Mary Kennedy
   Sue Benolken
   John Kowalczyk
   Janice Cooper

Minnesota Department of Health
   Phyllis Wright Slaughter
   Sara Thorson
   Mary Wanniger
   Lola Jahnke

Minnesota Department of Children, Families, and Learning
   Norena Hale

Olmsted County Social Services
   Patricia Carlson

Gillette Children’s Hospital
   Judy Miller

HealthPartners
   Donna Zimmerman

The PACER Center
   Ceci Shapland

Private Physician
   James Moore
Case Study: Oregon

I. Background and Introduction

The State of Oregon implemented its Medicaid managed care program—the Oregon Health Plan (OHP)—in early 1994 under a Section 1115 waiver approved by the federal Health Care Financing Administration (HCFA). The first phase of the program, which enrolled children, pregnant women, persons receiving Aid to Families with Dependent Children (AFDC) benefits, and new eligibles covered under the demonstration, garnered significant national attention due to its use of a limited benefit package based on a “Prioritized List” of covered services and treatments chosen by a multi-disciplinary panel of health care providers, researchers, and policymakers based on their effectiveness, cost efficiency, and perceived value to the community. Under Phase II, implemented in January 1995, OHP continued to gain notoriety by becoming one of the first statewide Medicaid managed care programs to mandatorily enroll the Supplemental Security Income (SSI) population. Today, the program represents a model through which virtually all Medicaid populations, including children with special health care needs (CSHCN), are enrolled into mainstream managed care organizations (MCOs) that are responsible for meeting all of the acute and ambulatory health care needs of their enrollees for a fixed, capitated fee. The only significant service categories “carved out” of the responsibility of MCOs are mental health and dental care. Medicaid has also recently organized its service delivery and financing of these services organized within fully-capitated arrangements with managed behavioral health organizations and dental plans.

A. Structure and Approach to the State Site Visit

The development of this case study began with the detailed review and extraction of information from Oregon’s approved HCFA 1115 waiver and its standard Medicaid contract with MCOs. Following this, to further establish our baseline understanding of the functions of OHP, generally and with regard to CSHCN, we conducted “core” telephone interviews with the Director of the Department of Human Resources’ Office of Medical Assistance Programs.
OMAP). This agency is responsible for administering OHP. We also interviewed the Director of the Child Development and Rehabilitation Center (CDRC) at the Oregon Health Sciences University (OHSU), and the Title V program component responsible for CSHCN. Based on these officials’ recommendations, we then contacted a broad range of key informants and arranged in-person interviews with them to occur during a three-day site visit in September 1998. Specifically, we met with:

- State officials representing the programs and divisions of child and family services, early intervention and special education, developmental disabilities, and mental health;
- Local public health, early intervention, and special education officials from the counties surrounding Salem;
- Private physicians representing both pediatric primary care and the Doernbecher Children’s Hospital;
- Representatives of three MCOs under contract with OHP—Kaiser, Regence Blue Cross/Blue Shield, and CareOregon; and
- A group of parents of children with special health care needs assembled by the Oregon chapter of Family Voices.

As a final step of the site visit, we convened a focus group composed of the state and local officials and providers identified above for the purpose of sharing our findings, discussing the strengths and weaknesses of OHP, and brainstorming on strategies for improving cross-system service integration for children with special health care needs and their families. (A list of key informants is included in Appendix A.)

B. Organization of Report

In the remainder of this report, we describe the Oregon Health Plan and assess the degree to which its design, structure, and implementation facilitate effective service integration for children with special health care needs. In Section II, we review in more detail the model of managed care implemented in Oregon, including: how it identifies CSHCN and enrolls them in
MCOs; provides pediatric primary and specialty care; supports families with care coordination and case management services; and links with other systems of import to CSHCN and their families, including children’s mental health, early intervention, special education and other community based support. Finally, in Section III, we present cross-cutting lessons learned regarding the OHP model and its strategies for meeting the multiple needs of CSHCN and their families in a coordinated and integrated fashion.

II. The Managed Care Model

By the early 1990s, the State of Oregon possessed significant experience with both commercial and Medicaid managed care, especially in urban areas of the state. Thus, as policymakers were designing the Oregon Health Plan, they were confident of both the state’s capacity to support and their ability to manage a statewide, fully-capitated Medicaid managed care system. To the extent possible, these designers wished to avoid both population and service carve-outs, opting instead to streamline their model and concentrate within plans as much responsibility and accountability for meeting the full range of service needs of all Medicaid groups, including people with disabilities, as possible.

Today, almost all state residents living at or below 100 percent of the federal poverty level, as well as children under age six in families with income below 133 percent of poverty and pregnant women with incomes below 170 percent of poverty, are eligible for OHP. Eligible persons must choose to enroll in one of 14 participating health plans; enrollment in capitated managed care is mandatory in almost all of Oregon’s counties. Health plans receive a single capitated payment per member per month (with 20 different rate cells reflecting cost differences by age, eligibility category, and geographic region) in return for covering enrollees’ needs for...

---

45 The first phase of Oregon’s Children’s Health Insurance Program, implemented in July 1998, extended OHP eligibility to all children through age 18 living below 170 percent of poverty.

46 Overall, approximately 280,000 persons are enrolled in capitated arrangements while between 8,000 and 10,000 are enrolled in PCCMs.
any of the 574 condition/treatment pairs currently covered by OHP. Once again, mental health and dental services are the only ones explicitly carved out of the routine responsibility of MCOs.

As discussed above, OHP began enrolling SSI eligibles, as well as children in foster care arrangements, in 1995. Before doing so, however, state officials engaged in a year-long planning process designed to ensure that health plans were adequately prepared to extend high-quality care to these special populations. This process involved representation from all state agencies serving people with disabilities (including the Departments of Public Health, Developmental Disabilities, Special Education, Mental Health, and Children and Family Services, among others), as well as medical directors and staff from each of the MCOs participating in OHP. While individuals with disabilities and their families were not directly involved with this planning, numerous advocacy organizations representing these groups were active participants. As a result of this process, a number of strategies were incorporated into the OHP design in an effort to safeguard special populations and permit plans to be more flexible and responsive to their needs, including:

- An “opt out” provision for persons whose mandatory enrollment in managed care would disrupt existing provider relationships;
- A requirement that plans designate “Exceptional Needs Care Coordinators” to be available to persons needing help in arranging and coordinating their access to care; and
- A special ombudsman program for individuals experiencing difficulty gaining access or coverage to needed care through OHP.

The following sections will examine in detail the findings of our case study and report on the extent to which it appears that efforts such as those described above have resulted in a managed care model that provides comprehensive and integrated services to CSHCN and their families. The discussion is organized to address, in turn, issues surrounding identification of CSHCN and their enrollment into managed care, receipt of primary care, specialty care, and assistance with care coordination, and links between OHP and other systems of care.
A. Identification and Enrollment of CSHCN

From an operational standpoint, the Oregon Health Plan defines children with special health care needs as those who are on SSI. While state officials acknowledge that there are additional children with chronic illnesses and disabilities that do not meet SSI eligibility criteria, and that some of these children are certainly enrolled in OHP, they have developed no other definition of the population nor implemented any special screening effort to identify CSHCN for service planning or monitoring purposes. Certain protections have been added to the OHP enrollment process for SSI eligibles, however.

Generally, all persons found eligible for OHP are provided with information on available plans and an application with which to enroll with a plan; the state does not use an enrollment broker to assist persons with the selection process. While Oregon has a policy of random auto-assignment for persons who do not select a plan, state officials are pleased with the fact that a relatively small proportion of eligibles—under five percent—are assigned to plans in this manner.

For SSI recipients, however, the state follows alternative procedures intended to protect them from potential adverse outcomes from the enrollment process. Initially, SSI recipients are treated the same as all others; they are provided with information on plans and asked to make a selection. (To preserve free and open competition among health plans and to protect plans from adverse selection, the state makes no special attempt to identify plans with special pediatric capacity nor to steer CSHCN to such plans.) However, during the Medicaid eligibility process, if an SSI recipient indicates any problems or disruptions that might occur as a result of their enrollment into managed care, social services caseworkers are instructed to counsel them more closely on the identification and selection of a plan that might meet their needs. In addition, SSI recipients who fail to make a selection are not auto-assigned to a plan; rather, this event triggers a response from a social services caseworker who is supposed to follow up with the SSI recipient, inquire about the delay in plan selection, and provide further advice and counsel. Under OHP’s “opt out” provision, an exception to mandatory enrollment can be granted to
disabled individuals to allow them to maintain ongoing relationships with providers who do not participate in any of the plan networks, to continue ongoing treatment protocols, or in cases when a change in physicians could seriously harm the individual. This provision has been used by a substantial proportion of SSI recipients; it is estimated that between 65 percent and 75 percent of all SSI recipients are enrolled in capitated health plans, with the remainder receiving care in PCCM or traditional fee-for-service arrangements.

As a further protection for disabled persons transitioning into managed care, Oregon developed the Continuity of Care Referral Form. This form, distributed widely among state and local agencies that work with these populations, is supposed to be filled out by caseworkers, caregivers, providers, or family members on behalf of persons with special need who have enrolled with an OHP plan, and serves to highlight the nature of their condition and potential need for special care. Plan representatives are, in turn, required to respond to these Continuity of Care Referrals by contacting the individual or family and, to the extent needed, generate a plan of care on their behalf. Completion of a Referral form is not mandatory for state and local agency staff serving persons with disabilities.

Overall, OHP’s performance with regard to identifying children with special health care needs and assisting them with enrollment into plans with appropriate capacity to meet their needs received mixed reviews from key informants interviewed for this study. On one hand, the model was praised for containing important safeguards that extend extra choice counseling to SSI recipients, allow for “opting out” if enrollment in managed care is deemed as having excessive potential for disrupting care, and for having a mechanism for identifying new enrollees with special needs and highlighting those needs to plans. On the other hand, the system was criticized for performing in an essentially reactive manner to exceptional cases that “rise to the top,” and/or to individuals who are knowledgeable and assertive enough to take advantage of these safeguards. Furthermore, an identified weakness of the model is that it targets these safeguards to only a small subset of all CSHCN—those meeting the categorical definition of the SSI program—and that no proactive or systematic effort is made by either state agencies or plans to identify CSHCN based on some other, more inclusive criteria. Finally, some informants believed that the model placed undue priority on the maintenance of open competition and the
avoidance of adverse selection among MCOs, at the expense of families’ access to health plans that might have specialized capacity to meet their needs.

Parents participating in our focus group tended to echo these latter concerns. They reported that the enrollment process was a “guessing game,” and did not feel like they had adequate information to make informed choices. In an attempt to address this and related concerns, the Oregon chapter of Family Voices, called *Families as Participants: Working within a Managed Care System*, worked with the Oregon Institute on Disability and Development at OHSU to secure a federal Maternal and Child Health Bureau grant and develop *PASSPORT—Parents Accessing Special Services: a Program for Organizing Resources and Treatment*. This guidebook is designed as a user-friendly tool to help families of CSHCN to understand their options and effectively negotiate services in managed health care systems. It contains sections on understanding how managed care works, making plan choices, navigating the system, understanding the language, and a convenient space for organizing records of diagnoses, treatments, and services received. Unfortunately, while PASSPORT has been shared with all of the state agencies and health plans involved with OHP, funds have not been available to widely disseminate it to all parents in the state. Also, providers, plans, and state agencies have not aggressively employed the tool.

B. Access to Primary Care

Like all managed care plans, OHP is designed to provide each enrollee with a primary care “medical home,” that is, an identified provider that is responsible for providing routine well and sick care, monitoring patients’ ongoing health, and organizing the care they need. Gaining access to appropriate primary care has been identified as a common problem among CSHCN, in part, because meeting these children’s specialty needs often overshadows the priority placed on routine preventive and primary care. In addition, most health systems do not possess an adequate supply of primary care physicians with experience in serving CSHCN.
In this regard, once again, OHP received strong praise as well as some criticism. Key informants identified the program’s success in providing all children, including CSHCN, with a regular source of primary care as a major strength of the program. In addition, the program allows pediatric specialists to serve as a child’s primary care provider, under special circumstances, thus improving the model’s ability, at least theoretically, to extend appropriate and high-quality primary care.47

However, among all persons interviewed for this study, there was a strong sense that the system possesses far too few primary care providers who are willing, comfortable, and experienced in serving CSHCN. As a result, parents are reportedly often dissatisfied with the primary care their children receive and tend to gravitate toward the relatively small number of physicians who become “known,” through the parent grapevine, as good with CSHCN. These physicians, in turn, suffer significant economic impact from this adverse selection, as the primary care fees they receive from OHP plans do not recognize the extra time and intensity involved with caring for CSHCN and working with their families. Other physicians in the community, recognizing the complexity of providing thorough care to CSHCN and how time-consuming it is to work with these children’s specialty, early intervention, school, and/or mental health providers, often judge it to be economically unfeasible to take CSHCN into their practice to any significant degree. Generally, the need for restructuring fees to reflect the additional costs associated with providing primary care to CSHCN was identified, as well as a mechanism for extending training to primary care physicians in caring for CSHCN.

A final criticism of the model was the built-in disconnection between primary medical care and dental care. While not closely studied in this case study, the carve-out of dental services (not an uncommon arrangement among both private- and public-sector managed care systems) was described as a design that perpetuates the lack of integration between these systems.

47Many policymakers and providers have argued, however, that most pediatric specialists are just as ill equipped to serve in a primary care capacity as primary care providers are to serve CSHCN.
C. Access to Specialty Care

Praise for the medical care aspects of the Oregon Health Plan was extended to the program’s apparent ability to provide good access to high-quality pediatric specialty care. Program officials and plan medical directors expressed satisfaction with the breadth of pediatric subspecialty networks in most, if not all, OHP participating plans. Like many states, however, Oregon has struggled with distributional problems and access to specialty care in the eastern and other rural portions of the state; most specialists are concentrated in the greater Portland area and, to a lesser degree, in Eugene and Medford.

Interestingly, three design aspects of OHP that raise the potential for coverage problems have not seemed to generate significant negative results for CSHCN.

- First, the Prioritized List, which was initially labeled by skeptics as a potentially harmful “rationing” device, actually includes a very broad range of the types of care that CSHCN most often require, including physician, inpatient hospital, outpatient hospital, laboratory and x-ray services, medical supplies and equipment, and ancillary therapy services including occupational therapy, speech and language therapy, and physical therapy. In addition, the list covers home health, private duty nursing, nutrition counseling, and hospice care, among others. State officials, providers, and advocates alike report that very few coverage-related disputes have occurred in relation to the Prioritized List; specific exceptions noted by key informants were children needing repairs of club foot and tonsillectomies.

- Second, OHP’s waiver of sections of the Medicaid EPSDT statute (namely, the requirement that states cover all necessary treatment to address conditions identified during an EPSDT screen) has not seemed to result in any controversial gaps in coverage. Again, the Prioritized List has been sufficiently broad to cover most all needed care. As a back up, OMAP routinely tracks its grievance and fair hearings processing for evidence of coverage-related problems for CSHCN and other special populations.

- Finally, OHP does not use the Medicaid/EPSDT definition of medical necessity; rather, its standard for “medical appropriateness” mirrors language commonly found in commercial insurance products.48 During the planning of Phase II, Medically appropriate services and supplies are defined in OHP contracts as those required “for prevention, diagnosis, or treatment of a health condition, which encompasses medical, mental or dental conditions,
however, OMAP and other state agencies went to great lengths to sensitize health plans to the needs of CSHCN and other disabled populations, and to educate them with regard to the application of “medical appropriateness” criteria to these populations. Apparently, this preparatory effort paid off; state officials and providers related relatively few problems surrounding inappropriate denials of care based on medical necessity decisions. Family advocates were more likely to identify inappropriate denials as a problem.

One specialty care system that may have experienced a disproportionately negative effect of the implementation of OHP is the network of specialty clinics at the Title V program’s Child Development and Rehabilitation Center. Not all of OHP’s plans have contracted with CDRC’s network of specialists, and those that do have tended to pay rates significantly lower than those previously paid under fee-for-service Medicaid.

D. Systems for Care Coordination

One of the features added to OHP upon the initiation of Phase II enrollment of SSI populations was the Exceptional Needs Care Coordination system (ENCC). As discussed above, each participating health plan was required by law to make available “designated advocates” to assist elderly and SSI-eligible enrollees with coordinating and accessing needed care. However, these ENCCs are not the only providers of case management available to CSHCN; in fact, this service simply represents a new component of an existing patchwork of systems that extend care coordination support to CSHCN and their families. Some of the most prominent of these are summarized below.

- **Exceptional Needs Care Coordinators.** According to guidance provided by OMAP, plan-employed ENCCs are required to respond to requests for assistance from elderly and disabled enrollees within one working day. Their scope of responsibilities entails not only helping enrollees gain access to needed

---

or injury and which are: consistent with the symptoms of a health condition or treatment of a health condition; appropriate with regard to standards of good health practice and generally recognized by the relevant scientific community as effective; not solely for the convenience of an OHP client or a provider of the service or medical or dental supplies; and the most cost-effective of the alternative levels of Medically Appropriate service or medical or dental supplies which can be safely provided to an OMAP member or PCCM member in the contractor’s or PCCM’s judgement.”
medical and health-related services within the plan, but also assisting elderly and disabled persons in overcoming barriers to care in the community and coordinating their receipt of services in community-based systems.

During our site visit, we met with ENCCs at three plans and discussed, in detail, their approach to providing case management. Without exception, these individuals were highly trained health professionals (typically registered nurses), who understood well the challenges faced by CSHCN and their families and were committed to their roles as patient advocates and facilitators of access. Generally, ENCCs described their normal activities as involving:

Responding to requests for assistance from physicians, other providers both within and outside of the plan, state agencies serving children, and enrollees (or their parents) or, commonly, following up with enrollees based on the receipt of a Continuity of Care Referral Form;

Obtaining and following up on referrals from the OHP Ombudsman regarding enrollees who are experiencing difficulties receiving care;

Working by telephone with enrollees and system providers to arrange and coordinate appointments and/or the receipt of care, equipment, or supplies;

Facilitating the resolution of disputes over coverage issues; and

Following up with clients, again by telephone, to ensure that they had received the care they needed.

The ENCCs we met with also described the fairly limited reach of their programs, however. For example, Kaiser Permanente employed just one ENCC who was kept extremely busy serving her caseload of roughly 50 SSI children and adults. In total, however, this individual estimated that Kaiser served between 750 and 1,000 SSI enrollees, most of whom, she believed, could benefit from care coordination. While Regence Blue Cross/Blue Shield employed seven ENCCs in four sites, they, too, could serve only 50 to 60 clients each on an ongoing basis, reaching less than one-half of one percent of the plan’s Medicaid enrollees. Each of these providers readily acknowledged that their programs had the capacity to respond to only the most needy enrollees who were fortunate enough to access the ENCC assistance.

ENCCs across the various OHP plans do meet regularly to share ideas, experiences, and strategies for coordinating care, and reported that these sessions were extremely valuable. OHP provides health plans with additional compensation to support their maintenance of ENCC systems in the amount of $6 per SSI enrollee per month above and beyond the normal capitation rates.
CaCoon. CaCoon (CAreCOordinatiON) is another statewide case management program, targeted specifically to children from birth through age 20 with special health care needs and their families. Administered and funded by the state Title V/CDRC program, CaCoon is implemented through contracts with local health departments in all of Oregon’s 36 counties. Public health nurses at the local level work with CSHCN and their families, most often in their own homes, to deliver a range of services, including:

- Family and child health assessments, to assess physical, cognitive, and psychological functioning;
- Developmental screening, to assess and monitor growth and development and permit early referral for diagnosis and treatment;
- Emotional support to families experiencing the stress of raising a child with special needs;
- Care planning and liaison between the family and health care and social services agencies, to ensure that children are gaining access to the multiple and diverse services they need;
- Consultation and collaboration with a broad range of community-based providers, including primary care physicians, early intervention providers, special education teachers and therapists, etc.; and
- Advocacy, to support families and develop their self-sufficiency in negotiating the multiple systems of health and health-related services they need.

During our visit, we met with CaCoon care coordinators in the Marion County Health Department who worked out of the county’s MCH Home Nursing section. These individuals, each a registered nurse, described their involvement with CaCoon and a range of other programs for vulnerable mothers, infants, and children. For CaCoon, they receive referrals from primary care physicians, discharge planners at local hospitals, and self-referrals from families. Roughly half of their caseload are Medicaid recipients enrolled in OHP. The remaining are privately insured, with approximately 5 percent of families uninsured. The home visiting model utilized by CaCoon was described as significantly more intensive than the telephone-based support extended by the ENCC system; through extensive face-to-face contact, CaCoon coordinators work with the entire family for a year or more to assess their needs and functioning; support their growth, development, and self-sufficiency; and actively work with other community-based providers to facilitate integrated service delivery. Each care coordinator carries a caseload of between 60 and 80 clients and, collectively, they estimate that they reach about 60 percent of families in need in their county.
None of the work of the CaCoon coordinators is supported by contracts with OHP plans. Rather, core state funding from the state Title V program is bolstered by county general funding and fee-for-service reimbursement from Medicaid under the state plan’s Targeted Case Management option.

- **Community Connections.** Community Connections is another CDRC-funded effort designed to support more coordinated and integrated service delivery to CSHCN and their families, particularly focusing on the health and education link. The grant-supported network of Community Connections Clinics, now held monthly in all regions of the state, provides for multidisciplinary evaluation and care planning for children with unresolved and complex medical issues. With special education and school nursing staff typically in the lead, these clinics bring together primary and specialty pediatric providers, public health nurses, early intervention and special education providers and therapists, children and family services social workers, and parents to assess children’s needs from multiple perspectives and develop integrated plans of care, which are then distributed among all involved providers. Unfortunately, Community Connections was described as vastly underfunded and as reaching a small fraction of the children and families that could benefit from such multidisciplinary care.

The care coordination programs described above represent just three of those present in Oregon that are focused, at least in part, on CSHCN. Case management services were identified as part of several other systems, including Early Intervention, Developmental Disabilities, Services for Children and Families, and Mental Health. Each of these programs, however, like those detailed above, were described as having limited reach and as focusing rather narrowly on particular subsets of children and/or particular subsystems of care. Furthermore, with the possible exception of CaCoon and certain of the ENCCs, none of the care coordination programs were described as closely integrated with one another. Rather, they provided their assistance with little or no connection to the case management support being provided by other programs. Combined, these characteristics result in a system that places significant burden upon families for the overall coordination of their children’s care, a burden that many families are unequipped to bear.
E. Links to Other Systems

Beyond the health and medical care that is organized and delivered within OHP, CSHCN often draw upon and utilize services from a number of other systems of care outside of the Medicaid managed care program. These include mental health, early intervention and special education, children and family services, and developmental disabilities, among others. In this section, we provide brief descriptions of these systems and the extent to which they are linked with OHP.

1. Mental Health

Coinciding with the implementation of Phase II of OHP and the enrollment of SSI populations into managed care, Medicaid also began phasing in its managed mental health program. Since mid-1997, this program has delivered mental health services to OHP enrollees statewide through 12 contractors, four of which are affiliated with fully-capitated health plans under OHP and eight of which are separate systems. At the point of enrollment into OHP, individuals are provided with information about their mental health coverage and, depending on which health plan they choose, may be asked to select a behavioral health plan. (Persons who select a health plan that is also a subcontractor for mental health, such as Regence, will also receive their mental health care from that plan; persons who select a health plan without a behavioral health subcontract, such as Kaiser, must select an additional organization from which to receive their mental health care.) The arrangement was described by key informants as a “clean” carve-out, that is, the mental health plan is responsible for all services related to mental health needs, and enrollees need not obtain a referral from their primary care provider in order to access their mental health benefit.

To many observers, the new managed mental health system represents a significant improvement over its county-based predecessor. Prior to managed care, Medicaid used the “rehabilitation services” option to cover mental health services on a fee-for-service basis, and the only providers permitted to participate were community mental health agencies under contract with counties. This restriction severely limited access for Medicaid recipients,
especially in urban areas, and forced families to utilize a mental health system that was heavily focused on adults rather than children. Partly in response to a class-action lawsuit that claimed the state was not meeting its obligations under EPSDT to fully serve children, Oregon has worked hard to expand and enhance its systems for children’s mental health. Now, each of the participating mental health plans typically represent alliances of both public agencies and private practitioners, support a stronger infrastructure for data management and quality assurance, and offer a fuller continuum of care for both children and adults.

Yet by design, the mental health system is organizationally separate from the health system, and integration problems between the two are reportedly widespread. According to some providers and parents we spoke with, the model creates an “arbitrary separation of mind and body,” and little or no information flows between the primary health and mental health systems. This is due in part to the mental health organizations’ concern over patient confidentiality and unwillingness to share information with medical providers regarding the mental health care enrollees are receiving; this is especially the case when persons are enrolled in any of the eight behavioral plans that are not directly affiliated with OHP plans. Just as common an explanation, however, is the lack of routine channels or mechanisms for the two systems providers’ to communicate with one another.

As is often the case with service carve-outs, “boundary issues” have also arisen between physical and mental health providers over which system is responsible for covering certain services. Disputes most commonly surround the coverage of such services as crisis/emergency care, laboratory tests, and medications for behavioral conditions such as ADD and ADHD, and pediatric specialists have been frustrated by the requirement for all mental health referrals to be sent through the behavioral health plan, even when child psychologists may be located at the same tertiary facility.

In the end, parents with children who are challenged by both physical and mental health conditions report that they typically bear the burden of coordination between the two systems. Sharing clinical information and records, resolving coverage disputes, and coordinating appointments most often falls upon the parent. These consequences are known to state
Medicaid and mental health officials, and both are placing a high priority on improving linkages between the managed care systems. While representatives of both believe that the systems are far better coordinated than they were prior to managed care, they also admit that there is much work to be done before optimal integration is achieved.

2. Early Intervention and Special Education

Both the Part C/Early Intervention and Special Education programs are administered by the state Department of Education, with service delivery organized through regional Educational Service Districts (ESDs). Staff of the ESDs, who are divided between the two programs, include communication, behavioral, and nursing specialists who provide a full range of habilitative and rehabilitative therapy and other services.

At this time, there is little, if any connection between the Early Intervention and Special Education programs and OHP. Medicaid continues to reimburse for early intervention- and special education-type services on a fee-for-service basis (despite the fact that most are on the Prioritized List that health plans are responsible for covering); both Early Intervention and Special Education can bill Medicaid directly for the services they provide to OHP enrollees (although Early Intervention has little history of doing so); and none of the health plans participating in OHP contract with ESDs to provide ancillary therapies. Unfortunately, it is also reported that no information regarding the care that is provided to CSHCN is ever exchanged between the ESD and OHP systems.

The most significant negative outgrowth of this lack of integration relates to the unclear boundaries between the systems and financial incentives that have, according to some sources, led many health plans to inappropriately refer large numbers of children needing therapy to the public school system. These referrals have increased the demand on systems that already lack an adequate supply of ancillary therapists.

The ESD managers we spoke to did participate in the Community Connections program, run out of Title V/CDRC, and praised the cross-system coordination that it facilitated. Citing this
example, they expressed considerable concern that the current system was fragmented for most children and that this fragmentation was undermining the overall quality of care provided to CSHCN.

3. Services for Children and Families

The Division of Services for Children and Families (SCF) is Oregon’s child protection/child welfare agency, responsible for providing services and supports to children in the juvenile justice system and foster care. Children eligible for SCF services who are also eligible for Medicaid—roughly 80 percent of all SCF children—have been enrolled in OHP since the program’s inception. At the local level, branch offices of the state are staffed with caseworkers charged with a broad range of responsibilities, including monitoring program eligibility and placing children with foster parents. In addition, each local office employs a designated OHP “expert” who is trained in the workings of the program and serves to link SCF children with an appropriate OHP plan and with community health care providers.

Since implementation of OHP began, SCF children’s access to primary care has reportedly vastly improved; this difficult population of troubled children now enjoys access to a “medical home” to the same extent as other children. However, OHP has succeeded much less well in extending to these children the behavioral health care so many of them need. Given that a disproportionate share of children involved with SCF have mental health needs, the lack of integration between these two systems has serious implications for this population.

4. Developmental Disabilities

The Division of Developmental Disabilities was one of the agencies most actively involved in the planning for Phase II of OHP; leadership within the Division possessed significant expertise in building high quality, family-centered programs for children and adults with developmental disabilities and played a key advisory role in helping design a managed care model that could effectively respond to the complex needs of disabled persons.
Interestingly, the program now operates quite separately from the Medicaid managed care system. It traditionally provided a range of institutional and residential services for persons with serious developmental disabilities, but has increasingly worked to develop community-based alternatives in collaboration with Services for Children and Families and the Early Intervention and Special Education programs within the Department of Education. Today, DDD directly administers a small number of programs that operate outside of Medicaid managed care, including one for medically fragile children (a group of roughly 50 children explicitly carved out of OHP) and another which provides intensive in-home services for developmentally disabled children. The Division also supports a small case management program that provides mostly home-based support to families with these children.

III. Lessons Learned Regarding Service Integration

By designing and implementing a managed care system that enrolls SSI populations into “mainstream” health plans, Oregon officials worked under the assumption that all MCOs participating in OHP could be made to possess equal, or at least similar, capacity to serve persons with chronic illnesses and disabilities. Indeed, to help assure that this would be the case, state officials invested considerable time and energy in the planning of Phase II, working collaboratively with managed care representatives to discuss the special needs of these populations and to identify strategies that would extend them various protections. Today, after roughly four years of experience, many signs point to the conclusion that Oregon has largely succeeded in its goal to provide high-quality health care to persons with disabilities in a fully-capitated managed care environment. According to most key informants we interviewed for this study, OHP has succeeded in:

- Providing all Medicaid recipients, including those on SSI, with improved access to a primary care medical home;
- Forging stronger and more formalized links between primary care and specialty medical care systems;
Meeting well the diverse medical needs of Medicaid enrollees through its “prioritized list” of covered services;

- Broadening access to a wider array of mental health providers through its managed behavioral health system; and

- Establishing new mechanisms within managed care (or between managed care and state government), such as Exceptional Needs Care Coordinators, the Continuity of Care Referral Form, and the Ombudsman Program, to focus attention on the needs of disabled persons and help assure that they retain access to needed care within managed care arrangements.

Most important, however, are the voices of families that generally support the above conclusions. According to the results of a 1997 survey of nearly 10,000 parents of CSHCN, conducted by the Oregon Health Sciences University and co-sponsored by CDRC and OMAP, the majority of parents were satisfied with their children’s health coverage, their health plan, and OHP. Furthermore, parents gave high ratings to their children’s primary care provider and to the quality of the provider-patient relationship. With few exceptions, parents reported that access to and availability of primary care providers and specialists was good.

Beyond these generally high marks for the health care/medical aspects of OHP, however, much less favorable reviews were extended to the program regarding its ability to provide non-medical ancillary and support services, educational services, and mental health in an integrated and coordinated fashion. Indeed, HSR’s site visit revealed that most of the systems of care that families of CSHCN typically rely on that are not directly part of the health system—including Early Intervention, Special Education, and Mental Health, among others—operated quite separately from managed care organizations under OHP. The separateness of these systems created predictable problems with regard to referrals, information flow, and coverage boundaries. And, without a consistent or centralized infrastructure for intensive case management, families were typically left on their own to navigate and negotiate these multiple disparate and complex systems. Thus, ultimately, the model lacks strong cross-system integration.
Additional, more specific lessons learned regarding service integration under OHP are presented below.

A. State-Level Efforts at Interagency Coordination

Recognizing the challenges surrounding the enrollment of SSI recipients into Medicaid managed care, Oregon officials made a concerted effort to carefully plan in advance of the implementation of Phase II. As described above, this planning involved not only the many state agencies with relevant experience and expertise, but also representatives of managed care organizations and advocates for persons with disabilities. Several tangible results grew from this planning process which key informants consider to have significantly strengthened the managed care system for SSI recipients. These results included:

- A policy that would allow SSI recipients to “opt out” of enrolling in OHP if it could be demonstrated that such enrollment would significantly disrupt their continuity of care;
- The development of a new Continuity of Care Referral Form designed to be completed by state agency caseworkers to notify health plans of the nature of SSI recipients’ special health care needs;
- The requirement that each participating health plan establish an Exceptional Needs Care Coordinator to serve as an in-house resource for persons needing help in accessing care; and
- The creation of a new Ombudsman Program to provide OHP enrollees with an avenue for resolving differences with and pursuing complaints and grievances against plans over gaining access to covered benefits.

This productive interagency and public/private collaboration has continued during Phase II’s implementation, as OMAP convenes monthly meetings of the medical directors of OHP plans, quarterly meetings of OHP ENCCs, as well as quarterly meetings of ENCCs with local caseworkers from state agencies, to discuss ongoing implementation challenges.
Of note, however, the only agency that did not express satisfaction with their degree of inclusion in the planning of Phase II was CDRC, the Title V component responsible for children with special health care needs; CDRC officials reported that they tend to be viewed as a provider rather than a policy-making agency and that, beyond advising on the development of OHP’s Prioritized List, they were not closely involved with planning for SSI recipients’ enrollment into managed care. This situation has largely been rectified, however, as CDRC leadership believes they now have an open and constructive relationship with their colleagues at OMAP. Most recently, the two agencies have been discussing strategies for developing a broader CaCoon-like case management system for CSHCN enrolled in OHP.

B. Family Involvement in System Planning, Implementation, and Oversight

While the planning for Phase II involved several individuals from the advocacy community for persons with disabilities, it did not directly involve parents of CSHCN. Similarly, parents have not been directly involved with OHP policy development, implementation, or oversight on an ongoing basis. During our focus group of families of CSHCN, representatives of the Oregon chapter of Family Voices echoed this. The slow dissemination and inconsistent use of the PASSPORT manual by OHP plans serves as a good example of how the system is not taking full advantage of family efforts. In addition, the system’s overall lack of emphasis on family support services reflects the lack of recognition of the importance of these services for families. During our interviews, key informants from several state agencies, notably OMAP and CDRC, acknowledged that they could and probably should be doing a better job of drawing upon the input and expertise of families.

C. Systems for Identification and Enrollment

Like many Medicaid programs across the nation, Oregon defines CSHCN by their categorical qualification for the SSI program. State officials acknowledge that this program’s rather limited definition of disability fails to include many other CSHCN with less severe conditions, and they agree that no alternative definition or coordinated screening effort is in place to systematically
identify CSHCN enrolled in OHP. While such safeguards as the “opt out” provision, Continuity of Care Referral Form, ENCCs, and Ombudsman Program have all been implemented to protect SSI recipients, these mechanisms are not routinely available for other CSHCN. Thus, the major implications of both the limited definition and the lack of a systematic screen are that potentially large numbers of CSHCN remain unflagged in the system and, therefore, receive no special care planning or support to ensure that they receive comprehensive care in an integrated, coordinated fashion. This problem was identified by key informants as a serious shortcoming of the current managed care system.

D. Systems for Information Sharing and Referral

A critical underpinning of an integrated system is the widespread availability of up-to-date information about the various components of and resources provided by the system. In addition, to function in an integrated manner, a system must possess mechanisms to ensure the efficient and accurate flow of information between its various participants. From the consumer perspective, families involved in our focus groups described a serious lack of information describing the resources and services available to them; such comments applied to both OHP and the other systems with which they interacted, and were echoed by various key informants we interviewed. Parents stated that they were “on their own” to figure out what they could expect from managed care, and largely didn’t know where they could turn for help. Notably, the aforementioned OHSU survey of parents of CSHCN found that fewer than one-quarter of respondents knew of the existence of the ENCC program and its potential for helping them.

From the provider and administrative perspectives, OHP was praised as contributing to the development of more centralized and integrated information and referral systems; the centralized accountability that accompanies a fully-capitated system has placed health plans in a strong and flexible position to authorize services and share patient information among plan providers. Even using a definition of medical necessity that is more limited than that included in the Medicaid/EPSDT statute, plans have not been criticized for making an excessive number of inappropriate denials of coverage and/or placing such limits on services.
Importantly, this free flow of information does not extend beyond the boundaries of the OHP plans. As discussed above, the mental health “carve out” has resulted in two separate systems that do not communicate with any regularity about the individuals they both serve, and the complete separation between OHP and the Early Intervention and Special Education programs means that these systems all operate in isolation. In each of these cases, potentially important and useful patient care information is not shared by the various providers simultaneously serving CSHCN, and the opportunity to integrate and coordinate care, as a result, is missed.

E. Systems for Care Coordination

Oregon officials can be praised for having the foresight to identify the need for a special case management system targeting SSI recipients enrolled in OHP and for establishing such a system. However, the ENCC system was observed to possess many significant weaknesses, including its essentially reactive nature, its dual focus on adults as well as children, its reliance on telephone assistance rather than in-person assessment, care planning, and assistance, and its overall lack of capacity which results in its serving the small fraction of individuals and families that are skilled enough to seek out and obtain its support. In addition, conflicting reports were given on whether ENCCs view their mission as simply coordinating the care that enrollees receive from the health plan, rather than coordinating all of the service needs of an individual or family.

Beyond the ENCC program, Oregon’s systems possess a patchwork of other case management services, most limited in scope in terms of the populations they serve or the service needs they address. Only the CaCoon Program, funded and administered by CDRC through contracts with local health departments, distinguished itself as a truly comprehensive and intensive system of care coordination specifically designed for CSHCN and their families.

During a focus group of state officials and OHP providers, much discussion surrounded the issue of whether Oregon needed a single, centralized case management system for CSHCN. While participants were in agreement that the multi-plan, mainstream model of managed care employed by OHP dictated that multiple systems of case management should be maintained,
they also agreed that these systems needed greater capacity, more consistent protocols, and more sophisticated data and information systems support. At the time of this writing, CDRC and OMAP officials were discussing the possibility of establishing a Targeted Case Management Program for CSHCN, using the CaCoon model and service delivery system; such a development would promise to inject much needed financial support for expanding this apparently effective model of care coordination.

F. Financing Systems

In pursuing the development of more integrated systems through managed care, Oregon has not tackled the extremely tough and complex challenge of blending funding streams across public programs serving similar populations. Despite the very strong interagency collaboration and planning that supported the development of OHP’s Phase II, the various programs serving CSHCN retain their individual budgets and fund their activities separately.

Oregon officials and managed care providers are relatively satisfied with the funding system that has been created to support OHP plans. At the time of our site visit, OMAP’s capitation approach was not risk adjusted; it included 20 different rate cells based on enrollees’ eligibility category and county of residence. With early implementation experience under their belts, OMAP officials were reviewing the strengths and weaknesses of alternative risk adjustment methodologies, including the Disability Payment System developed by the Medicaid Working Group, and were developing risk-adjusted rates for disabled populations not on Medicare.

The major weakness identified in OHP’s current financing structure was its inequity with regard to reimbursement for primary care physicians serving CSHCN. While not a decision dictated by state policy, the rates typically paid by plans to primary care physicians do not vary by the patient’s eligibility category. Therefore, no differential is paid to a doctor conducting a routine well- or sick-child visit with a “normal” child (usually five to ten minutes in duration) versus a child with multiple and complex needs (which reportedly can take 40 to 60 minutes).
This payment approach creates significant disincentives for primary care physicians to serve CSHCN, as doing so is often economically unfeasible.

G. Systems for Quality Assurance and Monitoring

State officials described the Oregon Health Plan as one of the most scrutinized managed care systems in the county; all of the controversy generated by the design of this 1115 waiver program has resulted in multiple studies of its impact on recipients’ access, utilization, and the quality of care they receive. However, despite this scrutiny, OMAP has incorporated no special efforts to measure or monitor quality of care for CSHCN, as a subset of the program’s enrollee population. Oregon is not alone in this case; methods and approaches for rigorously monitoring quality of care for this population are just emerging, and Oregon officials have been diligent in using available means to ensure as high a quality system as possible. For example, the OHSU/OMAP statewide survey of parents of CSHCN enrolled in OHP, conducted in part to satisfy evaluation requirements under Oregon’s 1115 demonstration waiver, was the first of its kind. In addition, OMAP has begun collaborating with CDRC in response to their offer to develop clinical practice guidelines for various conditions common among CSHCN. Most recently, a registered nurse position was added in the Medical Director’s office within OMAP to specifically serve as the point person for issues related to children with special health care needs and ENCC policy related to children.
Appendix A: Key Informant List

The following persons were interviewed by researchers of the National Policy Center for Children with Special Health Care Needs in their study of the Oregon Health Plan and its service of CSHCN.

Office of Medical Assistance Programs
Department of Human Resources
Hersh Crawford
Terry Layman
Jim Rowland
Judy Van Osdol
Carol Misrack
Jean DeJarnatt
Patti Vega
Toni Aguilar

Willamette Educational Services District
Carol Anderson

Child Development and Rehabilitation Center
Oregon Health Sciences University
Chuck Carter
Cathy Renken

Community-based Pediatrician
George Miller

Doernbecher Children’s Hospital
Art Jaffe
Kaiser Health Plan
Sharon Christianson
Care Oregon

Division of Developmental Disabilities
Department of Human Resources
Tina Kitchen
Carol Romm
Karen Johnson
Regence/HMO Oregon

Division of Child and Adolescent Mental Health
Department of Human Resources
Madeline Olson
Ralph Summers
Allen Johnson
Kate Williston

Office of Services to Children and Families
Charlene McCreight
Penelope Smith
Jane Hatch

Family Voices
Becky Adelmann
Jane Allm
Lauren Bridge

Marion County Health Department
Case Study: Tennessee

I. Background and Introduction

Tennessee’s Medicaid managed care program, TennCare, is a mainstream, fully capitated model that requires all children, including SSI eligibles and other CSHCN, to enroll in managed care plans. TennCare, one of the first and most closely scrutinized Medicaid managed care programs in the nation, was implemented rapidly after approval of an 1115(a) waiver in January 1994. Proposed in a time of rapidly rising Medicaid expenditures, TennCare has been widely credited with saving the state from bankruptcy. In addition to enrolling all Medicaid eligibles in managed care plans, the program expanded health care coverage beyond traditional Medicaid eligibility standards to include all uninsured children up to age 19 whose individual family incomes are below 200 percent of the Federal poverty level (FPL) and adults who are uninsurable or uninsured due to work displacement. TennCare has successfully extended coverage to nearly one million Tennesseans and has a current enrollment of approximately 1,299,466, of whom 826,719 are Medicaid eligibles and 472,747 are in the uninsured/uninsurable categories (TDH, 1999).

Prior to the implementation of TennCare, there was little commercial or Medicaid managed care experience in the state and little experience with managed care for CSHCN. Special care for CSHCN was provided by the Tennessee Department of Health Children’s Special Services (CSS), the state’s Title V program, through local health departments. CSS traditionally provided comprehensive medical treatment to children from birth to 21 years of age with a disability and/or chronic illness requiring medical, surgical, dental, hospital, outpatient clinic, rehabilitation, domiciliary or any other service needed to assist eligible children to overcome the defects for which they are being treated, and with family income of 150 percent or less of the FPL (Petersen, 1998). However, CSS has since shifted its focus from the provision of direct services to CSHCN to assuring services and enrolling CSHCN into TennCare.
To further explore the TennCare system, we conducted telephone interviews with senior TennCare and Title V officials and a three-day site visit to Nashville in August 1998. During that visit, HSR interviewed officials of the Departments of Education, Health, Children’s Services, and Mental Health and Mental Retardation; providers from the Nashville Part C/Early Intervention Program, CSS Clinics in the Metro Health Department, and Division of Mental Retardation; representatives of two health plans; and families of CSHCN. A list of key informants can be found in Appendix A.

The remainder of this report is divided into two sections. The first section provides information on the TennCare model, including: its structure; financing; eligibility and enrollment systems; provisions for primary care, specialty care, and mental health services; support services; case management; and links to other important systems of care for CSHCN. The final section provides a synopsis of the lessons learned from the case study regarding service integration for CSHCN in a mainstream Medicaid managed care system. In particular, lessons related to state-level interagency coordination, family involvement, identification and enrollment of CSHCN, systems for referral and information sharing, service coordination, funding, and quality assurance will be highlighted.

II. The Model

A. Overview of the Model

TennCare is a statewide mandatory program for Medicaid-eligible and uninsured Tennessee residents, including those whose medical condition makes them uninsurable. Medical services for TennCare recipients are provided under contract with nine health maintenance organizations (HMOs) for a fixed capitated amount per recipient per month. The HMOs, in turn, contract with a network of providers, including Federally Qualified Health Centers (FQHCs), at capitated or fee-for-service rates to offer acute and specialty care services to all recipients.

49 There were 12 HMOs under contract with TennCare at the time of the site visit, but several have since consolidated. Phoenix Health Plan, one of the plans interviewed, has merged with two other health plans and changed its name to the Xantus Corporation.
TennCare also contracts with 20 local health departments to provide access to health care services in rural areas.

In addition to acute and specialty care services, TennCare provides behavioral health services to Medicaid-eligible children through a service “carve out” known as the TennCare Partners Program. TennCare Partners offers a comprehensive package of behavioral health services, including mental health and substance abuse treatment, to all eligible recipients through a contract with two Behavioral Health Organizations (BHOs). The state contracts with the BHOs to deliver mental health services to assigned enrollees based on a set capitation rate. The two BHOs operate statewide and are each aligned with a set of health plans.

Tennessee’s Medicaid managed care system is overseen by the TennCare Bureau. This Bureau was originally established as a division of the Tennessee Department of Health, but in 1995 was moved to the Tennessee Department of Commerce and Insurance (TDCI) to enhance the financial and systems oversight of the health plans participating in the TennCare Program (TDCI, 1998). Here the agency was known as the TennCare Division. Realizing the importance of a system to oversee the quality of care provided by the health plans, in 1997, the state re-established the TennCare Bureau within TDH. This agency was given responsibility for administering the TennCare Program and monitoring the quality of care delivered by the MCOs to enrollees. These two oversight agencies—the TennCare Division within TDCI and the TennCare Bureau in TDH—work together to ensure that the health plans maintain their contractual obligations to the state of Tennessee, thereby improving the overall implementation of the program.

**B. Eligibility, Identification, and Enrollment**

As mentioned above, all Medicaid-eligible children, including CSHCN, are enrolled in managed care plans under TennCare. TennCare offers services to all Medicaid-eligible persons, all children under age 19 with no access to health insurance and with a family income under 200 percent of the FPL, dislocated workers who previously had health insurance through employers and became uninsured due to a bona fide closure of a business or plant, and persons with proof
of uninsurability. Since TCHIP was implemented in 1997, an estimated 27,000 uninsured children have been enrolled in TennCare.

An applicant can be enrolled in TennCare through several means. Those in the “uninsurable” category may enroll through the mail, the uninsured are enrolled through the local health departments, and Medicaid-eligible individuals are enrolled by the TDH. Medicaid and Tennessee Children’s Health Insurance Program (TCHIP) recipients may enroll in a plan at any time, but uninsured may only enroll during designated open enrollment periods. All enrollees have a choice of at least two managed care plans in their area. If an enrollee moves to an area outside of their plan’s region, the plan is responsible for helping the enrollee to find and enroll in a plan in the enrollee’s new area.

TennCare has no consistent system for identifying CSHCN or channeling them into particular managed care plans. If enrollees need help choosing a plan, TennCare attempts to identify a plan that includes the recipient’s provider, without favoring one plan over another. Plans are required to mail to all recipients a marketing package that will help them choose a plan. If recipients do not choose a plan, they are randomly assigned to one in their geographic region. For the most part, family members are assigned to the same health plan, with a few exceptions. SSI-eligible enrollees, including children, may choose a different health plan after their initial choice or assignment. Recipients may also file a grievance in an attempt to change health plans at a time other than an enrollment period.

Parents interviewed for this case study felt that TennCare enrollment and disenrollment policies did not adequately address the needs of families of CSHCN. Parents report that they are not given sufficient information on the health plans to help them identify those that are capable of providing specialized services to their children, nor are they given information on which providers have expertise in dealing with CSHCN. Many other key informants concurred, reporting that plans had too much responsibility for education of enrollees. Instead, it was suggested that the TennCare Bureau conduct a new member orientation forum where enrollees could obtain detailed information about the concept of managed care, TennCare health plans, and provider networks.
There is no formal definition of CSHCN used by TennCare; thus, plans are not able to distinguish these children among their enrollees. The only category that they are able to track are those with specific “high-cost chronic conditions,” such as AIDS and organ transplants, for whom plans are paid an additional fee. This mechanism will be discussed in more detail in Section III.

C. Primary Care

An essential element of the TennCare model is the provision of a “medical home” to all enrollees. Each enrollee has an identified primary care provider who is responsible for authorizing all needed services. Families choose their child’s primary care provider from a plan’s provider network; a pediatric specialist may serve as a primary care provider, with the plan’s approval. However, plans and state officials report a shortage of pediatric providers within the plans’ networks, and family physicians or other generalists are unlikely to have experience or expertise in treating even the routine health care needs of CSHCN.

All children, not just those traditionally eligible for Medicaid, are eligible to receive the full EPSDT package of screening, diagnostic, and treatment services. Although EPSDT services are offered to all children, the provision of preventive services has traditionally been a problem in Tennessee. Low EPSDT screening rates under the fee-for-service Medicaid program did not improve in the early years of TennCare, leading to a lawsuit brought by the Tennessee Justice Center in 1997. In 1998, after extensive negotiations, a Consent Decree was filed that detailed the steps the state must take to improve children’s access to EPSDT services and the deadlines by which these actions must be taken. Many of the Consent Decree’s provisions address primary care, including the following:

- TennCare will provide interperiodic screening, vision, hearing, dental, and diagnostic services that are medically necessary to determine the existence of suspected physical or mental illnesses or conditions;
The state will insure that the MCO networks are adequate in terms of qualifications and training, as well as numbers, to properly screen children in conformity with federal laws and regulations;

The state will take steps to ensure that each periodic screen accurately identifies children who should be referred for further assessment of behavioral/developmental problems and/or possible hearing or vision impairments. The development of referral guidelines will be completed within 18 months;

TennCare will provide education to the MCOs concerning the screening requirements;

Eighty percent of TennCare eligible children receiving screening by September 2001; and

Eighty percent of TennCare eligible children receiving dental screening by 2003 (State of Tennessee, 1998).

The above components were developed to assure that TennCare-eligible children receive regular screenings necessary to identify potential health, developmental, and behavioral problems so that they can be treated early to prevent further illness.

D. Specialty Care

All TennCare enrollees, including CSHCN, receive their specialty services through the health plans. Specialty care services are provided based on referrals by the child’s primary care provider and approved by the plan. As mentioned previously, TennCare plans are responsible for covering all Medicaid services to enrollees, including treatment services. However, complaints have been lodged regarding plans’ implementation of EPSDT’s treatment provisions and their use of more restrictive definitions of medical necessity than that provided in the Federal statute. These concerns were addressed in the Consent Decree by the establishment of several mandates. The Consent Decree gives a detailed description of all treatment services to be provided as medically necessary, including ancillary therapies, inpatient hospital services, respiratory care services, personal care services, and case management services. In addition, the Consent Decree requires the state to review MCOs’ practices in making decisions about medical
necessity and identify any practices that are inconsistent with federal law. Specific provisions of the Consent Decree include:

- The prohibition of limits on the amount, duration, or scope of services;
- Requirement of an expeditious process for approvals;
- The requirement that prior authorizations be made by qualified personnel with education, training, or experience in child or adolescent health; and
- The requirement that the plans develop a provider handbook regarding the provisions of medically necessary services. (State of Tennessee, 1998)

The health plans have networks of specialists and sub-specialists available throughout the state. However, families report shortages of pediatric specialists, particularly pediatric orthopedists, urologists and pulmonologists. These shortages require families to travel many hours to see an appropriate physician, to see an adult care physician in their network, or to seek a provider outside of their network and pay for the service themselves (NACH 1998). In addition to reported shortages for medical specialists, plans report difficulties finding adequate numbers of pediatric therapists. Parents and providers interviewed for this case study felt that it was difficult to obtain ancillary therapies within TennCare because of this problem.

E. Mental Health

As mentioned above, the system for providing mental health and substance abuse services for most children is described as a behavioral health “carve-out,” with mental health services provided through the TennCare Partners Program. (The only exception is children in state custody, for whom the Department of Children’s Services serves as the provider of behavioral health services.) All behavioral health services that were originally offered under TennCare, as well as those previously rendered through the Tennessee Department of Mental Health and Mental Retardation (TDMHMR), are provided under the TennCare Partners program by one of two behavioral health organizations. Anyone enrolled in TennCare with a behavioral health need can be referred by their primary care provider to TennCare Partners, which will authorize services based on medical necessity. However, despite the intention to exclude mental health
services from MCOs’ responsibility, the plans are not required to refer to a BHO for behavioral health services. Rather, providers within the health plans can provide services if they are qualified to do so; they will then be reimbursed by the BHOs. Thus, the two categories of service are not completely distinct.

To separate the severely and persistently ill individuals from those with milder mental health needs, enrollees are classified into two distinct groups: the priority population and the nonpriority population (Chang et al., 1998). The priority population consists of those individuals whose functioning has been severely impaired over long periods of time, those who are currently severely impaired but for a shorter duration of time, those who are not currently severely impaired but who have been in the past, and children with serious emotional disturbance. The nonpriority population consists of children at risk for serious emotional disturbance, and those children in state custody or those with a moderate mental disorder (Chang et al., 1998). The priority population receives an “enhanced package” of services, and the nonpriority population receives a “basic package”. Services under the basic package include psychiatric inpatient services, outpatient mental health services, and inpatient/outpatient substance abuse services, among others. The enhanced package includes all services offered under the basic package in addition to 24-hour residential treatment, specialized crisis services, and case management with few restrictions. Services are provided on a continuum from inpatient/residential home treatment to outpatient treatment with some wrap-around services, based on a definition of medical necessity appropriate to each level of care.

Far from integrating mental and physical health care, TDMHMR officials report that the system of delivering mental health services is suffering under TennCare. Since the implementation of TennCare and TennCare Partners, the use of inpatient mental health services has increased and the use of community-based services has declined, despite the state’s Master Plan to encourage the reverse. Thus, it appears that plans are taking advantage of the incentive to shift the cost of mental health services for more complex cases to the BHOs, thus requiring the BHOs to devote a larger-than-expected percentage of their capitation payments to inpatient care.
Certain other mental health services are provided through the Tennessee Department of Mental Health and Mental Retardation (TDMHMR). The Department provides early intervention, prevention, family support, and advocacy services for children and adults with mental illness—those services that are unlikely to meet the TennCare definition of medical necessity—wrapping around the TennCare Partners benefit package.

F. Support Services

In addition to the support systems that any family needs in raising a child, families of CSHCN often require further support because of the additional needs created by a child’s chronic health condition or disability. In Tennessee, several sources of support services are available to families with CSHCN through various agencies. These include:

- TDMHMR. This agency provides a range of support services for individuals who meet specific eligibility criteria. These include the following:
  - The Consumer Family Support program, which offers services to families who have a member with a severe disability, provides outreach to locate families in need of services, distributes a newsletter to parents regarding services provided by TDMHMR, and sets up support groups for families;
  - Family Support Services, which provides respite care, nursing care, home care, day care, nutrition services and personal assistance to families of individuals with severe disability of any kind, limited to 2,000 families (with over 2,000 families currently on the waiting list); and
  - The Respite Care program, which provides planned and crisis respite care for families of seriously emotionally disturbed children through individuals who are selected by the families and trained at one of three regional centers.

These services are financed through appropriations separate from TennCare and are not necessarily linked to the TennCare or TennCare Partners plans. For example, the respite care program is not publicized through the BHOs, as the Department could not meet the demand that such referrals would stimulate.

- CSS. Although CSS no longer provides direct services to children, the program does provide support services to families through the Parents Encouraging Parents program, which provides referral and information to families of CSHCN,
generally for those with newly diagnosed children. This program serves as a clearinghouse for information on CSHCN.

Although these services are available in Tennessee, their accessibility may be limited because of insufficient funding, long waiting lists, and lack of overall awareness.

G. Case Management

There is no unified system of case management offered to CSHCN under TennCare. Instead, as described below, care coordination services are offered through a variety of systems, each of which tends to focus on one aspect of the child’s care. These systems include the following:

- **Primary Care Providers.** Primary care providers serve as the gatekeepers for the TennCare system and are responsible for coordinating all medical services for their enrolled clients. However, because of relatively large caseloads they generally do not provide the intensive level of care coordination often needed by CSHCN.

- **Health Plans.** TennCare plans often employ staff to help monitor the care of enrollees, especially children who are at high risk or developmentally delayed. For example, Phoenix Health Plan has case managers that deal with access issues, providing some information about outside services, and helping to make sure that children receive the services that they need in the home. However, these staff are often few in numbers and generally have large caseloads, therefore they do not consistently provide intensive coordination to all CSHCN in their plans.

- **BHOs.** The BHOs have on staff care managers who help enrollees to access services, as well as community case managers who help with issues such as transportation and school enrollment and provide day-to-day support. BHO care managers are assigned to specific facilities (i.e. hospitals, residential centers) and community care managers are contracted by the health centers and are assigned to specific children. If community case managers have problems in coordinating services, they generally contact the BHO care managers to request assistance in obtaining needed services for the child. The BHOs provide case management services based on the behavioral health package that the child receives—either the “enhanced” or “basic” package. Any child that has enhanced benefits will receive case management services. Those receiving basic benefits do not automatically receive case management, but they can receive it under EPSDT if it is deemed medically necessary. This systematic design, however, has not been implemented well. Many key informants expressed that case management
provided by the BHOs was weak, and services were not being coordinated with outside systems.

- **CSS.** CSS provides care coordination to all CSS-eligible children primarily through nurses and social workers, who work to coordinate services with outside agencies, but these staff tend to focus on obtaining needed services for the child and not coordinating existing services.

- **DCS.** DCS coordinates the services of all DCS children through staff case managers. However, the level of case management varies depending on which DCS program the child is in. For example, if the child is in foster care, they will advocate for the child with little case management from DCS, but if foster care encounters any problems in coordinating care for the child they will generally ask the DCS case managers for help.

- **TDMHMR.** This agency provides person-centered planning and coordination to individuals with severe disabilities who are eligible for a Medicaid waiver. These support coordinators are in an entity separate from all other services received by the child, and place emphasis on planning and coordinating care for the child, but services are limited to a small population of CSHCN.

- **Tennessee Early Intervention System (TEIS).** TEIS has service coordinators on staff who assist families in accessing the system and obtaining needed services. However, these coordinators spend much of their time locating financing and dealing with waiting lists for services.

As illustrated above, there are many delivery systems involved with TennCare that provide case management, but not in a manner that coordinates services across all systems, nor that provides intensive support to all children and families that are in need of these services. No comprehensive, centralized model of case management exists; therefore, the level of care coordination that CSHCN enrolled in TennCare receive varies depending upon the system in which they are enrolled. The lack of a systematic approach to case management was consistently described as one of the major problems with the TennCare model; this will be discussed further in the next section.

### H. Links to Other Systems

Given the complex needs of CSHCN, these children often receive services from a wide range of systems, including the medical care, special education, early intervention, mental health, and
children’s services systems. The remainder of this section will describe these systems of care and the extent to which they are linked to TennCare.

- **Special Education.** Special education services are provided through the Tennessee Department of Education, Division of Special Education, to all eligible children who have one or more of a list of conditions ranging from developmental delay to traumatic brain injury from ages 3 through 21. Services are provided to help the child benefit from education, including: transportation, hearing and vision services, counseling services, physical, occupational, speech/language therapies, and assistive technology among others. All services are provided based on an Individualized Education Program (IEP) developed by a multidisciplinary team consisting of at least the parent, child, teacher, principal, specialists, and other agencies as appropriate.

The Department of Education and the Department of Health have developed a joint program called Project TEACH, to help coordinate the care of special needs children, particularly those who are mainstreamed into regular classroom settings. Project TEACH is being piloted in several counties to coordinate special education and medical care. Through this project, a public health nurse serves as a care coordinator and is paid by the local health department. Because the local health departments are TennCare providers, these care coordinators have access to TennCare information systems and can coordinate care with the child’s plan and primary care provider. Most important, this coordinator is responsible for determining which special education services are medically necessary and assuring that the TennCare plan is appropriately billed for those services. This program was reported to have saved the Department of Education $1 million in its first year. TennCare has been supportive of this model; officials sent a memo to the plans explaining that they were required to pay for the medically necessary services provided in schools. Project TEACH officials would like to expand the project to all school districts in the near future.

- **Early Intervention.** Tennessee Early Intervention Services (TEIS) is a free service that provides information, referral, and continuing support for children from birth to age 3 with developmental delays. Children may be evaluated for developmental delays by TEIS, which will also coordinate services with the CSS program, TDMHMR, TennCare, or a private provider to obtain services for eligible children. Services are provided based on an Individualized Family Service Plan (IFSP) developed by a service coordinator with the family for all eligible children. Children are referred to TEIS by the SSI office, hospitals, or physicians, but rarely through TennCare plans.

For children enrolled in TennCare, providers of Early Intervention services can only be reimbursed for these services if they are in TennCare plans’ provider networks. This can be a challenge; in the Nashville area, few therapy providers
participate in TennCare. Another coordination problem is evident in the financing of Early Intervention services. At the time of the site visit, no interagency agreement was in place between the TennCare and TEIS programs allowing TEIS to pay for services denied by TennCare. Without this authorization, the program is forced to discontinue services when they are denied by the plan. Services reported to be frequently denied include physical, occupational, and speech therapies, home-based services, and assistive technologies.

- DCS. Children in state custody include those in foster care, adoptions, child protective services, juvenile after-care, and probation services. Approximately 90 percent of DCS children are eligible for TennCare services. For these children, DCS provides mental health services, drug treatment, treatment for sex offenders, counseling, and case management. DCS case managers help children to enroll in TennCare plans and have training in the TennCare system. However, providers are not always aware of the needs of DCS children, and access to pediatricians and specialists have been reported to be a significant problem. In addition, the plans are responsible for covering court-ordered services, although they may not consider these services to be medically necessary.

- Department of Mental Health and Mental Retardation. In addition to its responsibility for TennCare Partners, TDMHMR is responsible for the provision of services to individuals with neurobiological brain disorders, mental illness, and mental retardation/developmental delays. Services are provided to severely mentally ill (SPMI) adults and SED children and adolescents. TDMHMR provides a wide range of programs and services in residential, outpatient day treatment, habilitation, and community-based programs. Many services rendered by TDMHMR are paid for through a Medicaid waiver that allows for comprehensive services to be provided to those with mental retardation who require 24-hour care. This waiver covers long-term care services, assistive technology, and other services needed by the child and the family. Once the parents apply for the waiver they are automatically enrolled in TennCare to further ensure that they receive comprehensive care. However, determining whether the waiver system or the TennCare plan is the payer of last resort has been a major issue for TDMHMR, parents, and providers. Parents interviewed for the study felt that they were inappropriately being shuffled back and forth across systems because of boundary issues between TDMHMR and TennCare plans. TDMHMR is currently working on an interagency agreement to clarify some of these issues and reduce fragmentation of services.

III. Lessons Learned Regarding Service Integration
Tennessee’s Medicaid managed care system is a fully capitated model in which all children, including CSHCN, are enrolled in mainstreamed managed care plans. This model was designed to expand access to health coverage in Tennessee and to improve Medicaid enrollees’ access to care. However, the TennCare model was not designed with the a focus on CSHCN in mind; thus, there is no system in place to ensure that services are coordinated for CSHCN. In addition, no mechanisms were developed to assure that medical services were coordinated with outside systems. The lack of a systematic approach to case management severely hinders the system’s capacity to provide fully integrated services. This section focuses on lessons that were learned from the case study on the challenges of systems integration in a mainstream, capitated model.

A. State-Level Collaboration Efforts

TDH was not closely involved with the initial development of the TennCare model, largely because of its rapid implementation. However, since the TennCare Bureau was moved back into TDH, communication between the Medicaid and public health agencies has improved. TDH officials report that they are able to access information more easily and communicate between agencies more readily because of the structural reorganization of the Department. In addition, the development of the Consent Decree has really been a catalyst for improved communication between the agencies. Committee meetings give participating agencies an opportunity to communicate with one another and establish networking relationships to help foster collaborative initiatives.

Although these efforts are promising, some problems still remain to be resolved, including the lack of involvement by the BHOs and the relative role of TDH in the implementation of TennCare. Even though communication has improved between TennCare and TDH, significant room exists in enhancing collaborative efforts. For example, TDH officials feel that more interagency involvement with TennCare is needed to ensure comprehensive services for children, but the TennCare Bureau’s exclusivity has made this involvement difficult.
B. Systems for Referral and Information Sharing

An essential feature of a system is a mechanism for each of its components, including consumers, to communicate and share information with each other. Key informants reported that the TennCare model is weak in this area. For example, parents interviewed for the study felt that they did not receive enough information on how to navigate through the system. Because managed care is a fairly new concept to many TennCare families, key informants felt that time should have been taken to involve and educate families and providers about the intricacies of the TennCare system. Informants also reported an ongoing need for information about the changes in programs and services.

In general, the various programs and agencies that serve these families also lack systematic mechanisms for communication. Examples of gaps in communication include the following:

- **BHOs and DOE.** It was reported that BHOs do not communicate with outside systems such as Early Intervention and Special Education. This lack of connection causes fragmentation and duplication between BHOs and school-based mental health service providers.

- **Project TEACH and MCOs.** Education officials felt that the plans do not see Project TEACH as a valuable resource with regard to identifying special needs children and providing care coordination and other services through the school. This constrains the ability of the program to expand because they do not have the support of the plans at the local level.

- **TDMHMR and MCOs.** Officials and parents reported that information is not shared between TDMHMR and MCOs for children enrolled in both TennCare and the Medicaid waiver. This lack of communication causes confusion for families regarding which program is responsible for providing and paying for services.

C. Systems for Service Coordination

Sharing information between programs and agencies is one aspect of service coordination. The coordination of services on the client level can be supported by coordination on the state level,
through agreements and relationships among the various agencies and departments that oversee the system of care for CSHCN. On the whole these arrangements appeared to be lacking, often causing delays and denials in the delivery of services. Specific interagency coordination problems include:

- The lack of an interagency agreement between TEIS and TennCare to reimburse providers for services denied by plans, causing services to be delayed or denied completely; and
- The lack of coordination between DCS and TennCare in assuring a seamless system of care for children who move in and out of state custody, often resulting in fragmented services.

Key informants mentioned that one possible solution to problems like this was to establish an independent body to adjudicate disputes regarding payment for services. Key informants also suggested that a Memorandum of Understanding or other type of interagency agreement be established among all agencies to ensure that services will be coordinated at the state level.

On the client level, TennCare provides no real system of comprehensive service coordination for CSHCN. Instead, depending on the systems of care the child uses, a child can have several types of care coordination or none at all. For example, children in the Medicaid waiver receive extensive coordination and planning services, while those children enrolled in TennCare health plans receive minimal care coordination services, depending on whether or not they are high risk or developmentally delayed. When services are coordinated, it was reported that these contacts depended on personal relationships rather than formal connections between agencies. During an interagency focus group conducted for the study, participants discussed various options for consolidating case management, such as:

Option 1. Case management provided for CSHCN by CSS. Under this option, the CSS program would provide case management independent of the TennCare plans for all enrolled children who meet an agreed-upon definition of CSHCN. The advantages of this option are that the CSS program already has a high level of sophistication with regard to TennCare policies and procedures; a long history of identifying and addressing the needs of children with special needs and experience providing intensive case management to CSHCN; a functional
relationship with other components of the health care system, including MCOs, schools, and health care facilities; and is recognized as a strong advocate for CSHCN. One disadvantage of this option is that it adds another level of bureaucracy to the system of referral and authorization. Another is that CSS has a reputation for being more inclusive than exclusive in regard to approval of services, potentially compromising the agency’s ability to develop working relationships with managed care plans that are at risk for the cost of these services.

Option 2. Allow families to choose a primary case manager. Alternatively, families could be asked to designate a primary case manager from among those serving their child, or to choose anyone, including a parent, to be the coordinator of their child’s care. The benefits of this option are that the family is placed at the center of care, parents are given more flexibility in selecting a case manager, and case managers can reflect the varying needs of the child. The potential disadvantage of this option is that it would still provide varying levels of care coordination, and these levels might depend on the preferences of the parents rather than the needs of the child.

D. Financing

Both the HMOs and BHOs are paid on a capitated basis and in turn contract with their providers at a fee-for-service or capitated rate. Capitation rates are developed for six age/sex categories, with a separate rate cell for those in the Blind and Disabled eligibility category. No additional adjustments are made to reflect an enrollee’s level of risk. In addition to the capitation payments, a supplemental monthly payment is paid to plans for each enrollee identified as having a high cost chronic condition (HCCC); qualifying conditions include AIDS, organ transplants, and kidney and heart disease. These payments come from a legislatively appropriated fund of $40 to $55 million per year. Because of the rarity of the qualifying conditions in children, this fund is unlikely to cover substantial numbers of CSHCN. In general, plans report that the capitation rates are low, although most report profits under TennCare.

TennCare has always been a controversial program. While it has succeeded in insuring thousands of children, it has not tailored its services to the particular needs of any sub-population. Therefore, the system includes no specific provisions for the care of children with special health care needs. This population cannot be defined or identified within the plans, and
many of their most complex needs, including the need for specialty services and supports, are frequently delayed or denied. Moreover, state officials are only beginning to grapple with the need for interagency coordination, and families report a great need for better coordination at the client level. Here again, the managed care model employed in Tennessee presents a barrier to this coordination; the need for each community-based agency to develop relationships with each of the contracted plans in its area makes communication and coordination a complex task. Thus, to assure an integrated system of care for CSHCN, the next step for TennCare is to focus on issues surrounding service coordination, at both the state and the client levels.
References:


United States District Court For Middle District of Tennessee at Nashville.  Consent Decree For Medicaid-Based EPSDT Services.  Nashville: US District Court Middle District of TN, 1998


Tennessee Department of Commerce and Insurance, TennCare Division.  Duties and Responsibilities of the TennCare Division within the Department of Commerce and Insurance. (http://www.state.tn.us/commerce/tncardr.html) Nashville: TDCI, 1998.


Appendix A: Key Informant List
Appendix A: Key Informant List

The following persons were interviewed by researchers of the National Policy Center for Children with Special Health Care Needs in their study of Tennessee’s Medicaid managed care system for CSHCN:

TennCare Bureau
   Susie Baird

Department of Mental Health and Mental Retardation
   Larry Thompson

Department of Health
   Division of Maternal and Child Health
   Mary Jane Dewey

Premier Behavioral Health
   Jeff Wright

Department of Education
   Ken Nye

Vanderbilt Pediatric Clinic
   Dr. Ellen Clayton

Department of Health
   Division of Health Promotion
   Judy Womack

Phoenix Health Plan
   Mark Mahler
   Anne Moore

Tennessee Early Intervention System
   Greater Nashville District Office
   Linda Tyus and staff

Division of Mental Retardation Services:
   William Eddington

Family Voices
   Dara Howe and parent advocates

Children’s Special Services
   Metro Health Department
   Sheila McCloskey

Department of Children’s Services
   Marilyn Hayes
   Rebecca Montgomery