

New Opportunities, New Approaches:

Serving Children with Special Health Care Needs Under
SCHIP

Volume II: Case Studies

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June 2000

Volume II

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Case Study: California

I. Background and Overview

The state of California elected to implement a combined approach in designing its SCHIP program.¹ Title XXI funds were used to expand Medi-Cal eligibility for children and to create a separate state program called The Healthy Families Program. The Medi-Cal expansion raised the eligibility level for adolescents aged 14 to 18 to 100% of the Federal Poverty Level (FPL). In addition, the Healthy Families Program was created to cover children ages 1 through 18 with family incomes between 100% and 200% of the FPL.² The Healthy Families Program offers the same benefit package as that provided to state employees and is delivered through a system of county-level medical, dental, and vision plans. The Healthy Families Program is administered by the Managed Risk Medical Insurance Board (MRMIB), which was created in 1990 to advise the Governor and legislature on ways to reduce the number of uninsured and to manage particular health care programs, such as Access for Infants and Mothers (AIM) and the Major Risk Medical Insurance Program (MRMIP).

Children with special health care needs (CSHCN) who are enrolled in The Healthy Families Program and who have certain chronic conditions or congenital anomalies receive specialty services related to their conditions through California Children Services (CCS), the state's Title V program for CSHCN. These children receive primary health care services, including dental and vision care, through their Healthy Families plans, and receive specialty care from CCS-paneled providers or through CCS-sponsored Specialty Care Centers and Medical Therapy Units, which are reimbursed on a fee-for-service basis. Thus, for physical health care services, California's approach represents a service carve-out model. This approach was modeled after

¹ California's SCHIP plan was submitted to HCFA in November 1997, approved in March 1998, and implemented beginning 1 July 1998.

² Effective in January 2000, Healthy Families will expand eligibility to 250% of the FPL by applying income disregards.

that used under Medi-Cal's managed care programs, in which CCS-eligible children receive specialty care through the Title V system rather than through their managed care plans. The Medi-Cal carve-out was originally scheduled to phase out after an independent evaluation, but has been extended for an additional five.

Children who are diagnosed as being seriously emotionally disturbed (SED) receive additional services from county mental health departments. For mental health, therefore, California represents a wrap-around model. In an effort to knit these various health delivery systems together, MRMIB requires Healthy Families health plans to sign Memoranda of Understanding (MOUs) with county CCS programs and CMHDs. The specialty care and mental health delivery systems for CSHCN enrolled in Healthy Families are outlined below.

- **California Children Services (CCS)** is overseen by the Children's Medical Services (CMS) Branch of the Department of Health Services (DHS). The CCS program is administered locally by California's 58 counties and serves roughly 140,000 children. Thirty of California's largest counties are "independent," meaning they administer and manage the CCS program entirely at the local level. The remaining 28 smaller "dependent" counties are managed by DHS through regional offices, which assist the counties with eligibility determination and other administrative functions. The CCS program provides diagnostic and treatment services to children with one of a list of CCS-eligible conditions, and sponsors a number of multi-disciplinary Specialty Care Centers and Medical Therapy Units.
- **The California Department of Mental Health (DMH)** is responsible for overseeing the delivery of mental health services, but does not have a corresponding statewide delivery system. All mental health services are provided at the local level through CMHDs. While a central focus of the DMH and the CMHDs is the provision of services to Medi-Cal clients, these agencies also deliver services to other clients, including Healthy Families enrollees.

We conducted a four-day site visit in August of 1999 to gather information on the Healthy Families program, its benefits and service delivery systems for CSHCN. The first day of the visit was spent in Sacramento meeting with state level officials from the CCS Program, MRMIB, the Department of Mental Health, the California Institute for Mental Health, and staff of the Governor's Office and the Senate Appropriations Committee. The following three days were spent in Alameda and San Francisco Counties exploring physical and behavioral health services, respectively, for CSHCN. We interviewed representatives from the Alameda County

Department of Health, a provider network of community health centers, a community health center, an advocacy and research group, a managed care plan, a children's hospital, the San Francisco County mental health agency, and a child development center. We also interviewed parents of CSHCN enrolled in Healthy Families (some in person and some by phone).

It is important to note that because the CCS program is implemented at the county level, the state's 58 counties vary widely in how and where services are delivered for CSHCN. As a result, readers should not assume that the Healthy Families system for CSHCN as it exists in Alameda and San Francisco Counties represents the system throughout the state.

This report presents a detailed description of our findings. In the following section of the report, eligibility, outreach and enrollment issues are outlined, followed by the benefit package, service delivery system, financing arrangements, and quality monitoring and oversight provisions for CSHCN. The last section of the report examines some of the lessons learned from the program's first year of implementation.

II. The California Model

This section provides information on Healthy Families' policies and procedures regarding CSHCN. The discussion will also include California Children Services, the state's Title V program for CSHCN, and information related to the SED wraparound benefit, where appropriate. Observations of how these elements are being implemented in Alameda and San Francisco Counties are also included in this section.

A. Eligibility, Enrollment, and Outreach

Before children can receive the services they need, they must be identified and enrolled in the appropriate programs and systems. This section will describe the eligibility guidelines, enrollment practices, and outreach strategies for each of the Healthy Families system components that affect CSHCN.

1. The Healthy Families Program

Children ages 1 to 18 with family incomes between 100 and 200 percent of the FPL are eligible for the Healthy Families Program.³ In addition to the income requirement, children must not be eligible for full-scope Medi-Cal, must be U.S. citizens or eligible immigrants, and must live in the state of California. The Healthy Families Program uses gross monthly income as reported on most recent pay stub, a signed statement from the employer, or the *federal* income tax return to determine eligibility and allows deductions for child support, work expenses, and dependent care. It was originally estimated that 328,000 children would be eligible for Healthy Families. As of 10 August 1999, 152,000 children had been enrolled.

MRMIB has contracted with Electronic Data Systems (EDS) to conduct eligibility determination and enrollment functions for Healthy Families. At the start of the program, California implemented a combined Medi-Cal/Healthy Families mail-in application. The four-page application, which is now available in 11 languages, can be completed with the help of certified application assistants housed in a variety of entities, including physicians' offices, health clinics, nonprofit social service agencies, schools, and other community groups. Application assistants receive a \$50 fee for each approved Healthy Families application they submit.

Since shortening its joint Medi-Cal/Healthy Families application form, the state has also instituted a single point of entry. The combined mail-in application is sent to a Healthy Families post office box in Sacramento where applications are screened for The Healthy Families Program eligibility for the program is determined within seven business days. Written notification of acceptance or denial is sent to the family. If a child is found to be eligible for Medi-Cal (instead of Healthy Families) and if his or her parent did *not* check the "I do not want Medi-Cal" box on the application, their application is forwarded to the appropriate county Department of Social Services office within four business days, where the Medi-Cal application will be processed.

³ As of 24 November 1999, the eligibility standard for Healthy Families was increased to 250 percent of FPL, raising the estimated number of eligible children to 475,000.

Healthy Families has instituted a waiting period, which stipulates that children must be uninsured for a period of three months prior to applying for Healthy Families. However, California has allowed for some exceptions to the waiting period. If a child is no longer covered by insurance, but had employer-based health insurance in the last three months, he or she may be eligible for Healthy Families if:

- The parent lost or changed jobs;
- The family moved to an area where the employer coverage is not offered;
- The parent's employer no longer offers health insurance benefits; or if
- His or her COBRA (Consolidated Omnibus Budget Reconciliation Act) coverage ended.

A question on the Healthy Families application asks families if any of their children meet these criteria. MRMIB does not conduct any specific activities to verify the information related to these exceptions; however, families are asked to sign the application indicating that their answers are "true and correct."

The Healthy Families monthly premium is calculated based on family size, income, and the health plan they select. (Families receive a discounted premium if they select the Community Provider Plan, the plan that has the highest percentage of safety net providers in the county.) Families pay between \$4 and \$9 per month per child, up to a maximum of \$27 per family per month, and are sent a bill each month for their premium payment. Part of the rationale for requiring this premium contribution is to help MRMIB track the status of enrollees, so the agency knows when to discontinue monthly capitated payments to plans for families who have moved or otherwise left the program.

Healthy Families also adopted a \$5 co-pay for health services, in part to mimic private coverage in the hopes of making the plan more attractive to working families who may be unaccustomed to participating in publicly-sponsored programs. The co-pay is waived for all preventive services and for services related to CCS-eligible conditions and the SED wraparound benefit. MRMIB has capped families' annual co-pay contribution for health plans at \$250 per year;

however, families are responsible for tracking their expenditures and informing health plans when they have reached the \$250 maximum. There is no maximum co-pay for dental and vision services.

The Medi-Cal program of the California Department of Health Services administers the outreach campaign for Healthy Families/Medi-Cal for children. In an effort to inform the public about the availability of health insurance coverage for children, the Medi-Cal Eligibility Branch has conducted a statewide media campaign, sought and secured corporate partnerships and sponsorships, and has engaged in a number of public relations activities.⁴ These statewide outreach efforts for the Healthy Families/Medi-Cal program for children are aimed at the general population, and do not target families of children with special health care needs in particular, or tout the benefits available for these children through the CCS carve-out. County CCS agencies have made efforts to inform their uninsured enrollees of the availability of CCS coverage, and their staff evaluate their clients' eligibility for Healthy Families during their annual eligibility redetermination. This process will be described in more detail below.

2. The California Children Services (CCS) Program

As mentioned, CSHCN enrolled in Healthy Families receive services related to their chronic conditions through the CCS program. The CCS program serves children under 21 years of age who are determined to have a CCS-eligible condition, reside in California, and meet the program's financial criteria. The child must be determined to have a CCS-eligible condition by one of the program's medical consultants. To meet the financial eligibility criteria, children must either:

- Be enrolled in Medi-Cal or Healthy Families;
- Have family incomes below \$40,000 per year; or
- Have annual health care expenses related to their CCS-eligible condition that exceed 20 percent of their families' adjusted gross income, if that income level is

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Schwalberg R., Hill I., Bellamy H., Gallagher, J. *Making Child Health Coverage a Reality: Case Studies of Medicaid and SCHIP Outreach and Enrollment Strategies*. The Henry J. Kaiser Family Foundation. Washington D.C. September 1999.

over \$40,000.

The CCS program determines income on an annual basis using the families' adjusted gross income reported on the California *state* income tax return, and requires a copy of the state tax return as proof of income. Though the CCS program does not consistently collect and report statewide data, program officials estimate that approximately 2,000 of the 140,000 children enrolled statewide—or 1.4 percent—are also enrolled in Healthy Families. Approximately 75 to 80 percent of children enrolled in CCS are covered by Medi-Cal, and the remaining families either have no insurance or limited private insurance coverage, as CCS provides wraparound coverage for some families who have reached the limits on their private plans.

When designing the CHIP plan, officials estimated that 1 to 2 percent of all Healthy Families enrollees would also be enrolled in CCS.⁵ The 2,000 children enrolled in both CCS and Healthy Families represent 1.3 percent of the 152,000 total Healthy Families enrollees to date.

Providers are the primary source of referral into the CCS program. The required MOUs between Healthy Families plans and county CCS programs stipulate that Healthy Families plans must ensure that their providers receive training in the CCS eligibility requirements. When a county CCS program receives a referral for a child, either from the pediatrician, specialist, or managed care plan, the CCS program determines medical eligibility based on the child's condition using the definition of CSHCN in the state administrative code.⁶ A long list of conditions is included in this definition. The state's large, independent counties determine medical eligibility for CCS, while the smaller, dependent counties rely on regional office personnel to determine whether or not a child's condition falls within those eligible for the program. It takes roughly five days to determine eligibility for the CCS program.

After a medical determination is made, a county CCS social worker makes the financial

⁵ The relatively low rate of one to two percent was arrived at after taking into consideration the facts that infants up to one year of age—a population group with high prevalence rates in Title V CSHCN programs—are served through Medi-Cal and are not enrolled in Healthy Families, that mental health and developmental disabilities services are funded through other programs, and that Healthy Families' managed care plans provide care for children with certain chronic conditions, such as asthma.

⁶ "A physically handicapped child is a person under 21 years of age who has physical defects resulting from congenital anomalies, or acquired through disease, accident, or faulty development." Section 2901 of the California Administrative Code.

eligibility determination during a face-to-face interview with the parent. A child who is enrolled in Healthy Families is automatically considered income-eligible for CCS, but if the family loses eligibility for Healthy Families, they must bring in their state tax form to re-qualify for CCS.

Beginning in July 1998, in an effort to educate program staff and to assure appropriate referrals, the CMS Branch of the Department of Health sponsored introductory-level training sessions on the Healthy Families program in every county for staff of the CCS program and the Children's Health and Disability Prevention Program (CHDP), California's EPSDT program. In addition, most county CCS and CHDP programs completed the Healthy Families application assistant trainings. From the county CCS program's perspective, it is fiscally advantageous to identify and refer as many Healthy Families-eligible CCS enrollees as possible, as the county's share of service costs is considerably lower for children enrolled in Healthy Families. For CCS children who are not eligible for Medi-Cal, the counties are traditionally responsible for 50 percent of expenditures; when children are enrolled in Healthy Families, the county pays only 50 percent of the state's share of service costs, or 17.5 percent of total expenditures. Moreover, enrollment in Healthy Families offers access to a primary care provider, which many CCS-eligible children did not previously have.

When Healthy Families was first implemented, the Alameda County CCS program reviewed their caseload for uninsured families who may have qualified for Healthy Families. This produced fewer than 30 Healthy Families eligibles. They also sent a mailing to English-speaking families about the availability of the program, but received little response. Finally, the annual financial eligibility review that is required for CCS is viewed as an opportunity to educate families about Healthy Families and submit an application on their behalf. Because of the high cost of care for CSHCN, all the representatives from Alameda County who were interviewed for the case study believed that almost all CSHCN who are eligible for CCS and Healthy Families had already been identified.

3. SED Wraparound Benefit

Children enrolled in Healthy Families who are determined to have a Serious Emotional Disturbance (SED) are eligible for behavioral health wraparound benefits that exceed those offered through the CalPERS health benefits package on which Healthy Families is based. The definition of SED includes three components:

- Children must have functional impairments in two of four areas, *and*
- Have a mental health diagnosis, *and*
- Meet one of the following criteria:
 - Be at risk for out-of-home placement, *or*
 - Have a disorder that is likely to continue without treatment, *or*
 - Display a risk for violence, *or*
 - Meet special education eligibility requirements.⁷

State mental health officials estimated that three percent of Healthy Families children would meet this definition—the same as the proportion of children covered by Medi-Cal who access these services. Following the state’s assumption, one would assume that 4,560 of the 152,000 children currently enrolled in Healthy Families would be accessing this additional benefit. Due to delays in processing claims data, state officials do not have an exact count of Healthy Families children who have used this benefit.

Referrals to the Healthy Families behavioral health wraparound benefit can originate from a number of sources, including families, health plans, schools, social service agencies, physicians, departments of public health, and law enforcement officials. To assure that SED children receive care promptly, the CMHDs have had to educate plans on the definition and identification of these children. The lack of a standard referral source to the CMHD may undermine the state’s attempt to systematize and increase referrals into the CMHDs. Through a grant from the David and Lucile Packard Foundation, the California Institute of Mental Health (CIMH) is currently developing a referral protocol for the plans and the CMHDs to use. At this time, the form is being reviewed by the county mental health directors, MRMIB, and the plans.

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California Welfare and Institutions Code Section 5600.3

Once finalized, statewide trainings will be available regarding the use of the referral form.

After receiving a referral, county mental health departments conduct an assessment to determine whether or not an SED condition exists. As set out in the template MOU between Healthy Families health plans and CMHDs, the evaluations are to be completed within five days for children who are currently receiving inpatient care and within thirty days for other children. Once a determination is made, the CMHD sends an approval or a denial notice of the additional SED benefit to the health plan.

The CIMH is also working to improve the enrollment and service delivery for children in the Healthy Families program who need mental health and substance abuse services. Part of their charge is to market the SED benefit available through Healthy Families. Toward this end, information about the SED benefit has been added to the Healthy Families educational materials and focus groups were conducted with families in counties that have been successful in enrolling children in the SED benefit to determine effective outreach and enrollment strategies. In addition to the efforts of the CIMH, some CMHDs have certified Healthy Families Application Assistants on staff.

The San Francisco CMHD receives most SED referrals from plans and providers, with the majority coming from the San Francisco Health Plan, a plan composed of the traditional safety net providers in the area. Officials also noted that a large majority of the Healthy Families SED clients in San Francisco County receive services at one child development center in Chinatown. CMHD staff credited the Asian community in general, and primary care providers who serve Asian children in particular, with a strong commitment to obtaining health care coverage for these children.

B. Benefits

The Healthy Families benefit package for health, dental and vision care mirrors that provided to state employees. Thought by most to be a generous benefits package, there are few complaints regarding limited or excluded benefits. The major differences between Healthy Families and the

Medi-Cal benefits package are:

- Medi-Cal pays for non-emergency transportation, and Healthy Families does not.
- According to Federal law, children enrolled in the Healthy Families Program are not eligible for vaccines through the Vaccines for Children Program, as children enrolled in Medi-Cal do. Some Healthy Families providers report that they are unable to recoup their costs associated with providing immunizations to Healthy Families children, as the cost of a single vaccine may exceed an entire month's capitation payment.
- The Healthy Families Program has imposed limits on certain services, such as behavioral health services and therapies. For example, Healthy Families children may receive short-term therapy for a particular condition for no more than 60 consecutive days after the first session. If medically necessary, additional therapy services can be provided.⁸
- MRMIB has not included a definition of medical necessity in the contracts with Healthy Families health plans, though MRMIB officials stated that *most* plans use Medi-Cal's definition of medical necessity. Though this may be the case, Alameda County providers experience problems with plans that apply the standard commercial definition of medical necessity to their claims; they report particular problems with claims for therapies and audiology services.

CSHCN enrolled in Healthy Families and the CCS program are eligible for a full range of specialty services for *their CCS-eligible condition*. CCS provides diagnostic services, hospital and physician care, laboratory services, durable medical equipment, pharmacy, home health, orthodontic services, HIV testing and monitoring, follow-up services for high-risk infants, and physical and occupational therapy. Once a child is covered by CCS, limits on the Healthy Families benefit package for therapies do not apply to their CCS-eligible condition. Some medical case management services are available through the Specialty Care Centers and the county CCS programs, as well, and the CCS Specialty Centers offer limited psychiatric services for children if they are related to the child's CCS-eligible condition.

When children are enrolled in the Alameda CCS program, the referring physician is granted authorization for one year's worth of services. All hospital stays and surgeries require prior authorization, as do home health care, durable medical equipment, some pharmacy, and

⁸ The program originally limited mental health services to 30 inpatient days and 20 outpatient visits per year; however, these limits were eliminated under mental health parity legislation passed in late 1999.

maintenance and transportation services. CCS authorizations are shared with the CCS liaison in the Healthy Families plans. While the county CCS programs have the authority to implement utilization controls and caps on services, the Alameda CCS program case managers reported that they almost always follow physicians' recommended treatment plans. Providers confirmed the Alameda's CCS program's approach to authorization, though they noted that the CCS authorization process varied by county.

All children enrolled in Healthy Families are eligible to receive 20 mental health outpatient visits per year and 30 days of inpatient mental health care per year. Children who are determined to have SED are eligible for additional benefits from the county mental health department.⁹ The SED wraparound benefit is equivalent to that provided by Medi-Cal and includes different levels of care—individual, family, and group therapy, intensive case management, day treatment, crisis intervention, and residential treatment. Case management services for SED children are also patterned after the Medi-Cal case management model and include linkages, consultation, placement, and plan development. CMHDs are responsible for inpatient psychiatric care beyond the 30 days provided by the Healthy Families plan and for all outpatient services related to the SED condition. County mental health departments that provide these additional benefits for Healthy Families enrollees use the Medi-Cal definition of medical necessity.

C. Service Delivery System

Healthy Families is administered through a county-level delivery system. The Healthy Families Handbook describes 26 health plans, 4 dental plans, and 1 vision plan operating in different areas of the state. Each county has from 1 to 8 health plans, one of which is designated as the “community provider plan,” or the plan with the greatest proportion of providers who have traditionally served low-income and public health clients.

MRMIB took steps to review the adequacy of the plans' networks during the bidding and negotiation process. Seven of the health plans (Blue Cross EPO, Blue Shield, Health Net,

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According to those interviewed during the case study, an SED child can be referred to the CMHD at any time. It is not necessary for the child to first exhaust the outpatient mental health benefits available through Healthy Families.

Kaiser Permanente, UHP Health Care, Ventura County Health, and Universal Care) make their commercial networks available to Healthy Families enrollees, but most of the plans have constructed an enhanced medical network comprised of their medical network plus their PPO network. Those interviewed for the case study believed that the physical health networks of Healthy Families plans were comprehensive and provide good access, with the exception of some specialty providers, such as pediatric ENT physicians, orthopedists, and mental health providers.

As mentioned, MRMIB requires Healthy Families plans to sign Memoranda of Understanding with county CCS programs and CMHDs. The template MOU developed by MRMIB delineates the respective responsibilities of the agencies in areas such as provider training, composition of the provider network, case identification and referral processes, identification of a plan/program liaison, exchange of information, case management, quality assurance, and problem resolution. It also requires the plans to designate “CCS liaisons” to coordinate and track referrals and to meet regularly with CCS staff. At the time of the site visit, 296 of the 374 CCS MOUs and 140 of the 184 mental health MOUs had been signed. The outstanding MOUs have been attributed to the slow county-level approval processes and concerns regarding particular provisions of the MOUs being raised by some counties.

CCS services are provided through county-based networks of credentialed, or “paneled,” providers. Healthy Families plans are not actually required to contract with CCS-paneled providers, but are encouraged to do so. Almost all CCS-paneled providers contract with Independent Physicians’ Associations (IPAs), which may in turn contract with Healthy Families plans. However, county CCS programs must rely on health plans to inform them of the CCS providers who are in the plans’ networks. This hampers their ability to panel new providers in plans with a limited number of CCS-paneled providers and to coordinate with plans when referring children to appropriate CCS-paneled specialists. It is also possible that children would have to change specialty providers when they enroll in CCS (although if their regular specialist is CCS-paneled, they could remain in that provider’s care).

All children’s basic mental health services are provided through managed care arrangements

with health plans, while SED services are delivered through county mental health systems. The policy goal of the wrap-around benefit is to develop and support county systems as the experts in children's mental health services, rather than to develop this capacity in the private sector. CMHDs are responsible for developing their own provider networks, which are used for Medi-Cal and for Healthy Families. Most CMHDs reportedly contract out for professional services, but often retain the responsibility for case management and administration. Healthy Families health plans can opt to contract with the CMHD to provide the basic mental health benefit in addition to the SED wraparound benefit. In instances where the Healthy Families plan provides the basic mental health benefit, the provider network for the SED benefit may differ considerably from that available through the plan. However, in rural areas and small counties, the provider networks for the basic benefit and SED benefit are likely to be similar given the dearth of pediatric mental health professionals, a significant problem, according to many case study informants.

D. Information Sharing and Coordination of Services

All those interviewed during the site visit were impressed with the coordination that has taken place at the state level between MRMIB, the state CCS program, and the Department of Mental Health. Specifically, these agencies have worked together to develop and implement the MOUs between Healthy Families plans and the CMHDs and county CCS programs, and to create quality monitoring standards for CSHCN. However, case study participants voiced concerns that this coordination is not replicated on the county level. In particular, interviewees noted problems and inconsistencies with information-sharing and coordination of services.

- **Information-Sharing Between Local CCS Programs and Healthy Families Plans.** The template MOUs between health plans and CCS do not contain statewide standards for sharing information, although they do require coordination meetings between the two parties and the sharing of monthly lists of eligible children. For the most part, however, arrangements for exchanging information are left up to the local CCS program and Healthy Families plans. As a result, relationships between the CCS programs and Healthy Families plans vary. This was evident in Alameda County, where the CCS program has strong links to the community provider plan, but not to the three commercial plans. For example, the Alameda CCS program sends monthly data tapes containing

CCS caseload information to the Alameda Alliance for Health to aid them in identifying their clients who are enrolled in CCS. They also provide the Alliance with copies of all CCS provider authorizations. However, the CCS program has not yet developed systems for sharing this information with the other three plans in the county (whose Healthy Families caseloads are smaller).

Although they are receiving more information than other Healthy Families plans in Alameda County, representatives of the Alameda Alliance for Health lamented their lack of access to data on services provided to their enrollees by CCS. Without access to these data, which aid them in evaluating and adjusting their benefits and services, they say it is difficult to manage and monitor children's care. However, CCS officials are concerned that sharing of service and cost data would violate patient confidentiality.

- **Coordination Between Healthy Families Plans and CCS.** Information-sharing at the administrative level between programs is a key component of care coordination at the client level. Though the CCS/health plan MOU states that plans are required to coordinate a child's care with CCS and the CMHD, as well as the vision and dental plans, the particulars of how this is to be accomplished are not enumerated. The MOU simply states that the plan should develop policies and procedures that specify the respective responsibilities of primary and specialty care providers to ensure the proper coordination of care for CCS-eligible children and that CCS should provide case management services and share medical reports with the plan's primary care providers.

It appears, however, that there has been some diffusion of responsibility for the coordination function across the various programs. Though the plans are responsible for assuring coordination of care, informants believe that this responsibility has been largely shouldered by primary care providers (not the plans), who are not remunerated by CCS or Healthy Families for this additional service. The Alameda CCS case managers report that they assume the CCS specialty providers are in communication with the patients' primary care physicians, though we learned from health plan representatives that primary care physicians often do not receive follow-up information from CCS-paneled providers. The county CCS staff do perform some case management tasks, but with caseloads hovering at 500 children per caseworker, their role is one of utilization management rather than comprehensive care coordination. The CCS liaisons at the plans are similarly focused on generating and tracking medical referrals rather than overall coordination of services between the plan and CCS.

- **Coordination Between Healthy Families Plans and CMHDs.** Coordinating care across service delivery components also appears to be a problem for children receiving Healthy Families mental health benefits. Because children can be referred to the CMHD by so many different agencies, their primary care providers often don't know they are receiving mental health benefits. Also, issues surrounding patient confidentiality were reported to hinder efforts to coordinate a child's care with his or her other health care providers.

E. Payment

Healthy Families managed care plans are fully capitated. Premiums for each plan are determined through a negotiation process. In preparing their bids, health plans exclude costs for treatment for CCS-eligible conditions. Health plans also consider whether their proposed premium will exclude their plan from participating in the program in a particular county because it is 10 percent above the target rate, based on the “family value package” (the combination of the two lowest-priced health, dental, and vision plans). MRMIB contracts with PriceWaterhouseCoopers to evaluate the plans’ proposed rates.

The plans are then responsible for paying their enrolled providers. Plans’ payment arrangements with providers vary; some may be paid on a fee-for-service basis, while others may assume risk through capitated rates. Two major issues arose with regard to payment of primary care providers:

- **Adequacy of rates.** In Alameda County, community health centers that belong to the Community Health Care Network receive capitated payments for all primary and specialty care services to enrollees who use their centers. For the most part, Healthy Families enrollees served by primary care clinics such as community health centers were patients at these centers when they were uninsured. Therefore, the Healthy Families capitation payment represents a new source of income for the centers. Nonetheless, center administrators report that the rates they receive for these children’s care are so low as to threaten their financial stability.
- **Risk Adjustment for CSHCN.** Another critical issue for primary care providers who serve CSHCN is whether rates adequately compensate them for the additional time needed to serve children with complex needs. Although Healthy Families rates are not risk-adjusted, a model has been developed in Alameda County for assessing the risk associated with each child and enhancing providers’ rates for high-risk children. The Alameda Alliance for Health (AAH), the community provider plan in Alameda County, in collaboration with the Alameda County Committee on Children with Special Needs, has developed a Special Needs Risk Assessment for primary care providers to use in identifying CSHCN enrolled in Medi-Cal and Healthy Families. Providers are paid an additional \$15 monthly fee on top on the monthly capitation fee for serving a child with a “moderate” risk score and an additional \$30 per month for a child with a “high” risk score. In the first year of the form’s use, 600 screening assessments were submitted (for both programs), mostly from community health centers.

Payment systems create important issues for specialty providers as well. CCS pays its specialty providers on a fee-for-service basis, using Medi-Cal's rate schedule, through EDS, its fiscal intermediary. In this case, the amount of the rates is not as critical an issue as the process for approving and paying claims and the incentives inherent in the carve-out system. Because plans receive capitated rates and are not responsible for specialty care for CCS eligibles, their incentive is to refer as many enrollees as possible to CCS, and to avoid paying as many specialty claims as possible. Tertiary providers report that they are often caught between the Healthy Families plans, many of which deny claims for pediatric specialty care routinely pending a referral to CCS, and the CCS carve-out system. The hospital has begun to refer children to CCS upon admission, even if they know they are not eligible, so as to have a CCS denial on file to support their claim to the plan. Moreover, some plans have asked the hospital to hold bills until a determination is made by CCS, adding 90 to 120 days to the payment process. (This problem also arises when patients are referred to specialists; plans may request a CCS evaluation before they will authorize a specialty visit.)

Payment for wrap-around behavioral health services is more straightforward. Payment for services included the basic Healthy Families mental health benefit is included in the plans' capitation rates, and services related to the SED wrap-around benefit are reimbursed on a fee-for-service basis using Medi-Cal rates. Healthy Families plans may subcontract with CMHCs for the provision of the basic benefits, as is the case with the community provider plan in San Francisco. In this case, the county mental health agency receives a capitation rate of 98 cents per member per month for the basic mental health benefit, an amount its officials describe as a "trickle," but which generally supplants funds they would have spent from their county appropriation. The additional services provided to SED children are billed on a fee-for-service basis, providing a clear incentive to identify as many of their clients as possible as SED.

F. Quality Monitoring and Oversight

MRMIB has yet to develop a specific quality monitoring system for CSHCN. However, at the time of the site visit, officials were examining various strategies for encouraging optimal plan performance, as well as sanctions for plans that do not meet expectations. These include the

use of HEDIS quality indicators and may also include member satisfaction surveys. However, officials note that it will be difficult to attribute a family's satisfaction to the Healthy Families plan or to the CCS program, as they will be using both systems. Information about the referral process will come directly from the county CCS program and health plans.

A new CCS data system currently under development will allow DHS to review CCS authorizations and case management services. Some CCS Specialty Centers have already developed standard reports. The CCS program conducts a family survey and has a parent liaison on staff who is conducting trainings on family-centered care, which involve Healthy Families plans.

Before the advent of SCHIP, the CMHDs had developed extensive quality assurance systems for the provision of SED mental health benefits for Medi-Cal enrollees. Each county was required to create quality monitoring plans and conduct quality assurance reviews. Under the Healthy Families program, MRMIB is responsible for conducting quality assurance for the SED wraparound. MRMIB has adopted the HEDIS effectiveness of care measure for mental health, and requires plans participating in the Healthy Families program to report this measure. However, the scarcity of mental health measures used nationally by managed care plans has limited the number of such indicators that can be used. Through the Packard Foundation grant to the California Mental Health Institute, a set of recommended mental health indicators and data sources are being developed this fall. The committee charged with the development of these indicators is currently conducting a survey of health plans in partnership with MRMIB to determine the data that plans have available to them.

III. Lessons Learned

After a slow start, California has witnessed an increase in Healthy Families enrollment, in large part due to the state's efforts to simplify the application and create a single point of entry for enrollment, as well as the clarification received from the Federal government on the implications of enrollment for children in immigrant families. One year after the program was implemented,

California has enrolled nearly half of its projected Healthy Families caseload. Though CCS program data are not complete, the estimated 2,000 children who are enrolled in both Healthy Families and CCS approximates the state's original estimate of one to two percent of the total enrollment. In Alameda County, the 55 children who are enrolled in both programs constitute 1.7 percent of the county's total Healthy Families enrollment. Data are currently unavailable at the state level on the use of the Healthy Families SED mental health benefit, but the 88 children in San Francisco county who are receiving services through the SED benefit represent 1.7 percent of the total county Healthy Families caseload. However, the state's mental health officials had projected that three percent of Healthy Families children would access the SED benefit, indicating that the wraparound benefit may currently be underutilized in San Francisco. This issue is now being addressed by the CIMH through a grant from the Packard Foundation to market the SED benefit.

When asked to comment on the Healthy Families enrollment numbers for CSHCN, everyone interviewed for the case study appeared to be satisfied that the system was catching most children in need. Physical health providers believed that almost all CSHCN had been identified by both CCS and Healthy Families, as the high cost of care required by these children provides a strong incentive for plans to identify and refer them to CCS. Mental health providers also underscored the county's fiscal incentive to assess eligible children for the SED benefit available through Healthy Families. They explained that CMHDs were previously responsible for the full cost of children's mental health services, while the state now receives a 65 percent match. In fact, mental health providers in San Francisco believed that most children who are currently receiving the SED benefit had previously been served by the county as uninsured clients.

California's decision to implement a service carve-out for CSHCN enrolled in Healthy Families was made early in the SCHIP legislative process, was met with little or no resistance, and pleased public health officials, providers, advocates, and families alike. Figuring strongly in the decision was a concern for the well-being of children with special needs. Many policymakers and advocates believed that children with complex medical needs would not fare well in a capitated system that strives to control costs. In addition to considering the needs of the children, policymakers were under significant political pressure from providers, particularly

children's hospitals, to retain the current Medi-Cal/CCS model of serving CSHCN, in which hospitals were prominent players.

However, in the absence of a competing model in the SCHIP design process, little effort was made to address issues of service coordination at the administrative and patient levels—the major challenges associated with any carve-out program. These challenges are manifested in inconsistencies in referral protocols into both the CCS program and the SED benefit, inconsistent relationships between CCS and Healthy Families plans, the absence of a standard mechanism for sharing information between CCS and plans, the lack of a comprehensive care coordination component, providers' confusion in determining which program to bill, and the lack of communication among all three system components—mental health, CCS, and Healthy Families. Each of these is discussed in more detail below.

- **Inconsistencies In Referrals from Healthy Families to CCS.** Though most officials seemed pleased with the enrollment numbers, it is apparent that some coordination issues still affect enrollment into the CCS system for Healthy Families children. Alameda County advocates and providers report that specialists are more knowledgeable about CCS program eligibility requirements and make referrals more often than do primary care providers. In addition, it was reported that some specialists are confused about how to get CCS authorization, and sometimes mistakenly contact the Healthy Families primary care provider seeking authorization for CCS. Also, providers working in tertiary centers serving children from a large catchment area complained that CCS eligibility criteria differ in every county, making it difficult to learn when it is appropriate to refer children with certain conditions. It was suggested that CCS should sponsor additional educational sessions for providers to help ameliorate these problems.
- **Inconsistent Information-Sharing Arrangements Between CCS and Healthy Families Plans.** No statewide standards have been put in place regarding the sharing of information between the plans and county CCS programs. As evidenced by interviews conducted in Alameda County, this results in different arrangements between CCS and the plans, which appear to be based on history and personal relationships.
- **No Comprehensive Care Coordination Function.** Coordination problems also exist at the patient level. Because referrals to the CCS program and SED wraparound benefits can come from a variety of sources, Healthy Families plans are not always informed about all the services their beneficiaries are receiving. While Healthy Families plans may have a utilization review department, and CCS and CMHDs provide limited medical case management, no one agency is

carrying out the function of coordinating primary care, specialty care and mental health and other services for these children.

- **Onus for Determining Which Program to Bill Falls on Providers.** The carve-out has also caused confusion for providers who must manage the billing. According to a representative from a children's hospital, their staff must determine which program to bill—the Healthy Families plan, CCS, or Medi-Cal. While some plans are better than others when it comes to paying for specialty services, others are eager to let CCS pay for expensive specialty care. When a child is admitted to the hospital, they refer them to CCS to ensure that they do not fall through the cracks. If the child is denied on medical grounds for CCS, the hospital then bills the plan, delaying payment greatly.
- **Lack of Coordination Among Primary Care, Specialty Care, and Mental Health.** The lack of coordination of services does not end with the Healthy Families primary care provider and the CCS specialist, but is also seen between the physical health systems of care and the mental health wraparound benefits provided by CMHDs. CSHCN with both physical and mental health needs must access three separate systems of care—the Healthy Families plan, the CCS program, and the CMHD. It is unknown at this time how many children are currently utilizing both the CCS carve-out and the SED wraparound benefit.

Despite these problems with coordination at the local level, MRMIB, DMH, and CCS officials have been active in forging a collaborative relationship and trying to improve the coordination of their respective systems. State officials were credited with developing a positive relationship among three different entities and with creating effective template MOUs between Healthy Families plans and CCS and CMHDs. Several case study participants noted that these MOUs are an improvement over those put in place for Medi-Cal. In addition, many state and county officials report that their experience in implementing Medi-Cal managed care informed and improved the Healthy Families implementation process considerably.

All those interviewed supported the managed care carve-out for CSHCN specialty services. Several reasons for the system's popularity emerged: the arrangement preserves the structure established under Medi-Cal managed care, and it serves the interests of families and advocates who are leery of managed care as well as those of tertiary providers, who are concerned about their continued funding. Therefore, most informants preferred the carve-out approach for CSHCN to the alternative of including children with complex needs in a capitated system with built-in cost controls and incentives to manage access to services. Some even suggested that California should implement a population carve-out for CSHCN so that these children could

receive their primary health care services through the same system as their specialty care.

In sum, California's carve-out approach has both advantages and disadvantages. CSHCN have relatively open access to qualified providers through the CCS program that they may not have if they were limited to a plan's network, which might not have sufficient numbers of pediatric subspecialists. In addition to gaining access to appropriate providers, children and families benefit from the fact that the CCS program had an existing infrastructure of specialty physicians, clinics, and hospitals. Similarly, when designing the Healthy Families mental health wraparound benefit, policymakers aimed to further build upon and strengthen the county-based mental health infrastructure that already served this population.

On the other hand, it was acknowledged that California's complex county-based managed care system, coupled with the county-based CCS and mental health systems, contributes to a tendency toward fragmentation of services, and complicates the task of care coordination for CSHCN. The separate service delivery systems for the physical health carve-out and the wraparound mental health benefit adds another complicating factor to the challenge of coordination for families, providers, and plans. However, with continued partnership at the state level and the implementation of some of the initiatives currently in progress, issues related to referrals, coordination of care, and billing can be ameliorated. The unique challenges presented by a carve-out model that is implemented at the county level calls for strong state leadership and rigorous quality monitoring procedures to assure that CSHCN have access to and receive high-quality care.

Case Study: Connecticut

I. Background and Overview

The opportunity to expand health insurance for children was received enthusiastically in Connecticut, with representatives of the Governor's office, legislators, and child advocacy organizations all committed to the goal of providing coverage for children. Although the state had a budget surplus at the time, the Governor was unwilling to endorse a major expansion of Medicaid because of the risk inherent in an entitlement program. Therefore, the State Employees Health Plan was chosen as the benchmark for a separate state SCHIP program. However, policymakers and advocates alike were concerned about the adequacy of this package for children with special health care needs (CSHCN), so a wrap-around package was designed to provide additional physical and behavioral health services above the limits of the basic benefit package.

The plan for Connecticut's Title XXI program, known as Healthcare for Uninsured Kids and Youth (HUSKY), was submitted to HCFA in January 1998, approved in April 1998, and implemented in July 1998. The HUSKY model comprises four elements:

- **HUSKY A** is the state's new name for the Medicaid program for children. This program provides the full Medicaid/EPSTD benefit package to children through age 18 with family incomes up to 185 percent of the Federal poverty level (FPL). Prior to the passage of the SCHIP legislation, the Medicaid program covered children through age 13 with family incomes below 185 percent of FPL; under Title XXI, this coverage was expanded to all children through age 18 at this family income level.
- **HUSKY B** is Connecticut's separate state SCHIP program. This program provides coverage equivalent to that included in the state employees' benefit package to children with family incomes up to 300 percent of the FPL. No premium is charged to families with incomes between 185 percent and 235 percent of the FPL (known as Band 1); those with incomes between 235 percent and 300 percent of the FPL (Band 2) pay a premium of \$30 per child per month, up to a maximum of \$50 per family. In addition, families with incomes over 300

percent of the FPL may enroll their children in HUSKY B, but are charged the full premium rate. This is known as Band 3.

- **HUSKY Plus.** The Husky Plus plan represents a wrap-around model of services for children with special health care needs. Children in Bands 1 and 2 of HUSKY B with special physical or behavioral health care needs may be eligible for HUSKY Plus services (children in Band 3 are not eligible for the Plus program). This program has two components:
 - HUSKY Plus Physical provides payment for health care services not covered through the basic HUSKY B benefit package, such as hearing aids, adaptive and specialty equipment, and motorized wheelchairs, as well as family advocacy and care coordination to children who meet a standard definition of children with special health care needs. This program is modeled after the state's Title V Children with Special Health Care Needs program, which provides similar wrap-around and support services to qualifying children who are eligible for Medicaid (now HUSKY A). These benefits are provided through two contracted agencies: the Connecticut Children's Medical Center (CCMC) and the Yale Center for Children with Special Health Care Needs.
 - HUSKY Plus Behavioral covers in-home family counseling and therapy, crisis services, and care coordination to children with mental health and substance abuse problems. This program is administered under a contract with the Yale Child Study Center.

To explore this system further, we conducted a case study of the HUSKY program in July 1999. During a three-day site visit, we interviewed officials of the state Departments of Social Services and Public Health, the Children's Health Council, two of the three contracted managed care organizations, the state's enrollment broker, the contractors for HUSKY Plus Physical and Behavioral, and several parents of children enrolled in the Yale Center for CSHCN.

Representatives of the third managed care organization were later interviewed by phone.

This report presents a detailed description of our findings. The following section describes Connecticut's provisions for eligibility and enrollment in the HUSKY programs, their benefits and service delivery systems, their payment systems, and their mechanisms for monitoring the quality of care provided. The final section presents our analysis of these findings and the lessons learned by Connecticut officials in the first year of the HUSKY program.

II. The Connecticut Model

This section reviews the critical elements of Connecticut's programs for children with special health care needs, including HUSKY A, HUSKY B, both HUSKY Plus programs, and the Title V CSHCN program.

A. Eligibility and Enrollment in HUSKY A and B

Connecticut officials established broad eligibility standards for the HUSKY program. As mentioned above, the Medicaid eligibility standard was increased to 185 percent of FPL under SCHIP for all children through age 18, and HUSKY B was created to cover all children with family incomes under 300 percent of FPL.¹⁰ As will be discussed below, all children who are currently uninsured (and have not had insurance for the previous six months), and who are not eligible for HUSKY A, may enroll in HUSKY B; those who do not meet the income eligibility criteria may buy in at the full premium. It was estimated (based on information received from HCFA) that 89,700 children would be eligible for these programs: 53,000 for HUSKY A, 22,300 for the subsidized portions of HUSKY B (Bands 1 and 2), and 14,400 for Band 3. As of July 1999, 12,000 children had been enrolled in HUSKY A and 4,000 in HUSKY B. That is, for every child enrolled in HUSKY B, three had enrolled in HUSKY A.

A simplified, combined application process has been developed for the HUSKY programs. The state contracts with a private enrollment broker, Benova, to be the single point of entry to the program, and a single four-page application form is used for both programs. Because Federal law requires that the state Department of Social Services determine eligibility for Medicaid, applications that appear to be eligible for HUSKY A are referred by Benova to the appropriate regional DSS office. (Likewise, applications for HUSKY A received by DSS that appear to be eligible for HUSKY B are forwarded to Benova.) Benova operates a toll-free hotline to provide information about the HUSKY program and to assist families in completing applications

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This income standard exceeds the guidelines included in the Title XXI statute, which set SCHIP eligibility standards at 50 percentage points above the state's Medicaid eligibility level. In Connecticut, this would have limited eligibility to those with family incomes below 235 percent of FPL. The state used income disregards to increase the eligibility standard to 300 percent of FPL.

over the phone; supporting documentation must then be submitted by mail. Applications may also be mailed in.

The state has made a number of efforts to reach out to and inform families of the availability of the HUSKY programs; however, these outreach efforts have not highlighted the Plus programs and have not targeted families of children with chronic conditions. The toll-free hotline provides information about the program, and the state has used mass media, community-based, and one-on-one outreach strategies to promote both the program and the hotline. These include enclosing flyers with unemployment checks; educating pediatric providers in collaboration with the American Academy of Pediatrics chapter; and training staff at school-based health centers. The only outreach effort conducted by DSS that has been specifically aimed at children who are likely to be eligible for the Plus program was a mailing to those on the waiting list for the state's Katie Beckett waiver program.

To deter crowd-out, the state imposed a six-month waiting period for those who had previously been covered under employer-based insurance. Several exceptions to this waiting period are available:

- If the child lost coverage involuntarily, or if a parent changed jobs and coverage became unavailable;
- If “employer-based coverage” is through a self-employed parent;
- If the termination of coverage was due to “extreme economic hardship” on the part of the parent or his or her employer; or
- If lifetime medical benefits were substantially reduced under the employer-based plan.

If a child has been covered within the previous six months, Benova sends the family a rejection letter listing the possible exceptions. To qualify under one of these exceptions, a family would be required to call Benova to discuss their child's eligibility.

B. Eligibility and Enrollment in HUSKY Plus

State officials estimated that 8 percent of HUSKY B enrollees, or approximately 1800 children, would be eligible for HUSKY Plus Physical. At the time of the site visit in July 1999, approximately 20 children had ever been enrolled in the program. The estimate of the eligible population for the HUSKY Plus Behavioral program was 25 percent of those eligible for the Physical program, or 450 children; at the time of the site visit, seven children had been accepted into the program.

Outreach for the two HUSKY Plus programs is largely conducted by the plans and the program contractors, and eligibility is determined by the contracted providers: for the Physical program, Connecticut Children's Medical Center and The Yale Center for Children with Special Health Care Needs, and for the behavioral benefit, the Yale Child Study Center. Children are referred to these centers by their managed care plans if it is suspected that they qualify for one or both of the Plus programs or if they need a service not covered by the basic HUSKY benefit package. The following sections discuss, in turn, the eligibility standards and enrollment process for the HUSKY Plus Physical and Behavioral programs.

1. HUSKY Plus Physical

Eligibility for the HUSKY Plus Physical program is based on the definition of children with special health care needs established by the Maternal and Child Health Bureau:

“Children who have [or are at elevated risk for] chronic physical, developmental, behavioral or emotional conditions (biologic or acquired). They also require health and related services (not educational and recreational) of a type and amount not usually required by children of the same age.”

This definition was adopted in January 1998, when the state plan for the HUSKY program was submitted, and is now used for both the HUSKY Plus program and the Title V CSHCN program. Previously, eligibility for Title V was open only to those children with one of a list of 11 diagnostic categories, which did not include such conditions as respiratory diseases and cancer. The new, non-categorical definition considerably broadens the pool of children

potentially eligible for these programs.

Despite this improvement, no standard system is in place for operationalizing this definition. No screening questions are included on the application form, and Benova does not ask any questions about enrollees' health status or service needs when discussing enrollment. This was universally described as a consumer-protection provision; officials of both DSS and Benova were concerned that parents would be reluctant to discuss their children's conditions before enrollment, as they would fear discrimination or denial based on their child's health status. Thus, no attempt is made to identify CSHCN before they enroll in a managed care plan. Rather, the plans are responsible for identifying CSHCN and referring them to the Plus program.

The Department of Social Services has developed a referral form to be filled out by the plan and forwarded to the appropriate HUSKY Plus contractor for physical or behavioral services. (This form is included in Appendix A.) For children with physical health care needs, the form asks only for preliminary diagnostic information; it does not include specific questions intended to operationalize the definition of CSHCN used by the program. Each of the three plans appears to be using different guidelines for identifying eligible children, as described below.

- **HealthChoice/Preferred One.** In this plan, a member services representative is dedicated to the HUSKY B program. Children who have chronic conditions and who have reached the limit of their benefits are referred to the program; however, plan officials were unsure exactly what the Plus program covered, and were concerned that the plan would have to deny a service before a child could be served through Plus. Ten children enrolled in this plan are also enrolled in the HUSKY Plus Physical program.
- **Community Health Network.** In this plan, referrals to HUSKY Plus hinge on the list of diagnostic categories no longer used by the Title V program. The plan has developed a form listing these conditions; while the form also includes space to list the types of services and medications the child needs, these criteria are secondary to the diagnostic list. As of July 1999, three children enrolled in this plan were also enrolled in HUSKY Plus Physical.
- **Anthem Blue Cross/Blue Shield.** This plan reported some confusion in identifying children for the HUSKY Plus program. The plan's representatives described referring children either because of a service need that the benefit

package would not cover *or* because of a diagnosis that indicated that the child and family may need extra support services; however, because children are identified through the Utilization Management department, the latter group could not be identified without a specific claim. The plan reported that the Plus contractors, particularly CCMC, have encouraged them to refer as many children as possible, but they have been given no guidelines in identifying children who meet the program's broad definition of CSHCN. Plan representatives did not know how many of their enrollees had been referred to HUSKY Plus Physical.

The plans also described conducting a general screening process during their welcome calls to each new member. These processes vary in specificity; one plan focuses on issues such as pregnancy, substance abuse, and mental health needs in their screening questions, while another asks generally whether anyone in the family has special needs requiring the care of a specialist or other special services. The answers to these questions are generally used to make referrals to the plans' case management systems, but are not used to identify children who may be eligible for HUSKY Plus.

The plans' difficulty implementing the broad definition of CSHCN is borne out by the experience of the HUSKY Plus Physical contractors, both of whom reported that all of the children referred to them have had a specific service need at the time of referral. Rather than referring all children who meet the definition, on the assumption that the program's family support services can benefit any child with special needs, the plans appear to be referring only those children who need a specific service that is not covered by the HUSKY B benefit package.

2. HUSKY Plus Behavioral

As will be described in Section C below, the HUSKY Plus Behavioral program offers a wrap-around package of crisis intervention, care coordination, and home-based therapies to children with behavioral health care needs. The program was designed based on the assumption that 25 percent of identified CSHCN, or approximately 450 children, would have behavioral health needs at a level that would require these services. At the time of the site visit, ten children had been referred to the Behavioral program, seven had been accepted, and four children were receiving services (the parents of the other three voluntarily withdrew).

Initially, the program was to be limited to children who had used at least five days of inpatient care or 20 outpatient visits; the program's planners did not originally develop a referral system, as they expected these children to be numerous and easy to find. As recruitment proved more difficult than expected, a system was developed to identify and refer children to the program, and the minimum service requirements were waived. Referrals now come to the Child Study Center from the plans based on diagnosis and need for services (using the DSS form), and they are passed on to the contracted provider in the child's region for determination of eligibility. The Center has also provided training to the managed care plans' staff in the identification of children in need of wrap-around behavioral services. As in the Physical program, therefore, the referral mechanism depends on identification of a child by the managed care plan.

C. Benefits

The benchmark selected for the HUSKY B benefit package was the state employees' health plan. This section describes the differences between this package and the HUSKY A (Medicaid) benefit package, the benefits available through HUSKY Plus Physical and Behavioral, and those available through the Title V CSHCN program.

1. HUSKY A and B

The HUSKY A benefit package is, of course, governed by the Medicaid statute, and children are entitled to receive the full range of services covered by the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program. In theory, both HUSKY A and B use the same definition of medical necessity, which encompasses services "provided to correct or diminish the adverse effects of a medical condition or mental illness; to assist an individual in attaining or maintaining an optimal level of health; to diagnose a condition; or prevent a medical condition from occurring." This broad definition would include a wide range of diagnostic, habilitative, and treatment services. However, at the time of the site visit, the plans had not received a contract for HUSKY B. Without a formal contract, the plans are operating under different assumptions regarding the definition of medical necessity to apply to HUSKY B; one plan reported using the definition in their commercial state employees' benefit contracts, while the

others used the Medicaid definition. Thus, while no specific incidents were reported, it appears that service authorizations depending on determinations of medical necessity vary across plans and hold the potential for differentially affecting CSHCN's access to care.

The HUSKY B package is based on Connecticut's State Employees' Health Benefit Package and is somewhat narrower than that of Medicaid. The major differences between the two packages are:

- Non-emergency transportation is not covered under HUSKY B;
- HUSKY B imposes limits on specific services, such as inpatient care, behavioral health services, and therapy visits; and
- The EPSDT treatment provision does not apply to HUSKY B, so specific treatment services may not be covered.

The plans reported that they have never received clear guidance on the coverage limits under HUSKY B, such as definitions of "short-term rehabilitation" or a list of covered dental services. Therefore, the plans variously reported basing their coverage decisions either on the Medicaid package (minimizing the distinction between the two programs) or on a commercial package (risking limiting services inappropriately).

2. HUSKY Plus

The intent in creating the two HUSKY Plus programs was to provide services beyond those covered by the HUSKY B package that were likely to be needed by CSHCN and their families. As mentioned above, the HUSKY Plus Physical program was modeled after the Title V CSHCN program, which provides similar wrap-around coverage for children who are eligible for HUSKY A, with the goal of providing a total package (through HUSKY B and HUSKY Plus) equal to that provided to Title V-eligible Medicaid enrollees. The HUSKY Plus Behavioral program is an entirely new model, based on an approach developed by the Yale Child Study Center. This section describes, in turn, the benefits available through the HUSKY Plus Physical program, the Title V program, and the HUSKY Plus Behavioral program.

The HUSKY Plus Physical program provides services in two general categories: clinical services and support services. These include:

- **Clinical services.** The HUSKY Plus Physical program pays for clinical services not covered under the HUSKY B benefit package. Examples of services reimbursed through HUSKY Plus include equipment and supplies, home health services, and periodontal surgery.
- **Support services.** All children enrolled in HUSKY Plus Physical are offered family support, advocacy, and care coordination from one of the two contracted provider sites, the Yale Center for CSHCN and the Center for CSHCN at CCMC. These services provide broad support and care coordination, encompassing such issues as transition from Early Intervention to school, informing parents of services available in their communities, and communication with case managers and advocacy for families within managed care organizations.

These support services are described by parents as vital in helping them to manage their children's care and to assuring that they receive the services they need. The parent support groups run by the Yale center were described as excellent sources of information about providers who can care for CSHCN, and the program's advocacy and support role provide essential support and guidance in negotiating with providers and managed care organizations.

The services of HUSKY Plus Physical are nearly identical to those provided to Medicaid eligibles under the Title V CSHCN program, with two exceptions: the Title V program has recently added respite care to its service package, while the HUSKY Plus program covers motorized wheelchairs, which are not covered through Title V.

The HUSKY Plus Behavioral program offers a narrower set of "integrated community services" designed to supplement the behavioral health services covered under HUSKY B. These services include intensive case management, in-home psychiatric and substance abuse treatment, and 24-hour mobile crisis services, with the goal of addressing the needs of the family as a whole in order to avoid the need for inpatient or residential services. These support services are provided in conjunction with the traditional inpatient and outpatient behavioral health services provided through the HUSKY B plans. Thus, this model was described as a "true wrap-around," not a handoff of responsibility from one plan to another.

D. Service Delivery Systems

Under both HUSKY A and HUSKY B, services are delivered through managed care plans. Services under the HUSKY Plus programs are delivered through contracted agencies who oversee the delivery of services in all regions of the state. These delivery systems are described in turn below.

1. HUSKY A and B

At the time of the site visit, four managed care plans were under contract with the state Department of Social Services (DSS) to serve Medicaid/HUSKY A enrollees: Kaiser, Anthem Blue Cross Blue Shield, HealthChoice/Preferred One, and the Community Health Network. All of these plans except Kaiser also participate in HUSKY B. At the time of the site visit, contracts had not yet been executed for the HUSKY B program, but DSS officials reported that they expected the contracts for the two programs to be similar, including the same performance measures, sanctions, and grievance and appeals processes required under the HUSKY A program.

Although the HUSKY B plans also participate in HUSKY A, the provider networks they offer to their enrollees are not always the same. Fewer providers accept HUSKY B than HUSKY A, due to differences in the payment rates offered by the plans and the need to collect co-payments from HUSKY B enrollees. Thus, access to basic medical and dental services may be more limited under HUSKY B than HUSKY A. In the HealthChoice/Preferred One network, Danbury Hospital does not participate in HUSKY B. From the Community Health Network panel, only about two-thirds of the dentists who participate in HUSKY A are available to HUSKY B enrollees, and some of the primary care providers and specialists have declined to participate in HUSKY B as well. Anthem Blue Cross Blue Shield offers the same network to enrollees in both programs.

2. HUSKY Plus

The HUSKY Plus programs are administered by agencies in Hartford and New Haven, with

services provided through networks of providers throughout the state. These delivery systems are described below.

- **HUSKY Plus Physical.** As mentioned above, two contractors manage the services provided under the Physical program: the Yale Center for CSHCN, in New Haven, and the Center for CSHCN at CCMC, in Hartford. Enrollees choose one of these two centers to manage their care and provide support services; however, they may continue to receive clinical services from their community providers. In general, CCMC serves children in the northern half of the state and Yale the southern, but both centers are open to families statewide. The two centers are staffed similarly, with a range of nursing and social work staff, overseen by a Medical Director. Both also include “family resource specialists” or “family resource coordinators” who provide family support, advocacy, and coordination with special education and other community-based programs.

This system builds on that developed under the Title V CSHCN program. In 1996, this program was reoriented from its traditional Title V bill-paying function to a system under which these two agencies were contracted to oversee the delivery and management of services to eligible children within a fixed budget. These new contracts enabled Yale-New Haven Hospital and CCMC to develop multidisciplinary centers, which were able to provide a range of administrative and support services and to reimburse providers for clinical care. The Title V program currently serves approximately 600 children.

- **HUSKY Plus Behavioral.** This program is managed under contract with the Yale Child Study Center. The Center, in turn, contracts with a network of child guidance centers and hospital clinics organized in 10 regions throughout the state. Each of these centers is staffed by a Master’s-level clinician and a paraprofessional, under the oversight of a child psychiatrist who acts as Medical Director.

Several informants noted a common source of confusion about the HUSKY Plus service delivery system. Although the program maintains a statewide provider network and allows enrollees to continue to use their community-based providers, families may mistakenly assume that they will have to receive all of their services from Yale or CCMC once they enroll in the program. This misunderstanding may limit access to the HUSKY Plus Physical program.

E. Payment

The managed care plans participating in the HUSKY A and B programs are fully capitated. Under HUSKY A, capitation rates are governed by Medicaid regulations requiring that capitated payments not exceed the Upper Payment Limit defined by historical fee-for-service Medicaid expenditures. Rates are therefore developed by DSS based on the average fee-for-service expenditure for enrollees in each age group in each county, and all plans receive the same rates. In the case of HUSKY B, no such requirement, and no past expenditure experience, existed; therefore, the plans' rates were developed based on a bidding and negotiation process with the plans. The plans reported that they based their cost proposals on their Medicaid capitation rates and on other experience with subsidized coverage (such as Blue Cross's experience with the state-funded Healthy Steps pilot program), with some adjustment for the fact that the HUSKY B benefit package was more limited than that of Medicaid. The proposed rates were then negotiated with DSS, and in all cases the final rates were lower than the plans' original bids. Therefore, although the three HUSKY B plans receive different rates, all are lower than their HUSKY A rates for children in the same age categories.

In addition to the capitation payments to the plans, a separate fund of \$5 million was appropriated to be divided equally between the two HUSKY Plus programs for three years. (This appropriation includes the 65 percent Federal match under Title XXI.) For the Physical program, the \$2.5 million fund is divided between staff salaries and clinical services; each of the centers receives a budget to fund the salaries of care coordinators and other staff positions, and a common pool is administered by CCMC to pay for clinical services for enrollees in both centers.

For the Behavioral program, the Yale Child Study Center administers the entire fund of \$2.5 million, from which it funds a portion of its directors' salaries and pays its subcontracting providers on a fee-for-service basis. This payment mechanism presents a challenge for the program's subcontractors, who are required to maintain specific staffing arrangements, including a Master's-level clinician and a paraprofessional. The low levels of enrollment in the program have made it impossible for these positions to be self-supporting, potentially presenting

a serious challenge for the subcontracting agencies.

Connecticut's arrangements for delivering and financing care for CSHCN appear to balance the incentives presented to the managed care plans. On one hand, the capitated payments to the plans create the incentive to avoid enrolling children with complex conditions or, if that is not possible, to restrict access to costly services. While the HUSKY Plus program provides an outside resource to serve these children, the fact that the Plus programs only cover services that are not included in the HUSKY B benefit package mitigates the incentive to "dump" children on the Plus programs, an initial fear on the part of state officials. In fact, it is possible that the Plus program's intensive care coordination and family advocacy services create demand for services that are covered under the plans' benefit packages, presenting an incentive to avoid referring children to this program. However, this does not seem to be a major barrier to children's enrollment in HUSKY Plus.

F. Quality Monitoring and Oversight

Even before the Title XXI legislation went into effect, models for caring for CSHCN were in place through the Medicaid managed care and Title V CSHCN programs. Moreover, each of these programs had developed strategies for monitoring the care provided to enrolled children. However, these models have not necessarily been used to guide the development of a quality monitoring strategy for the HUSKY programs.

Under DSS's Medicaid contracts, managed care plans are required to provide encounter data as well as to submit data for specific outcome measures, including EPSDT screening rates and rates of dental visits. In addition, the state's contracted professional review organization, Qualidigm, will conduct a number of specific studies, including one on asthma, and the plans will administer the Consumer Assessment of Health Plans Survey (CAHPS) module for CSHCN this year. The reporting requirements are somewhat less extensive under HUSKY B; the plans are required to report on many of the same indicators, but are not required to submit encounter data. (This decision was attributed to a desire on DSS's part to make the HUSKY program resemble a commercial insurance line more than Medicaid.)

DSS has no specific plans as yet to monitor the provision of services under HUSKY Plus. However, a model for quality monitoring exists for this program as well, in the form of the Title V CSHCN program. Since the program was redesigned in 1996, an extensive reporting and oversight system has been in place through the Department of Public Health (DPH). This system includes the following elements:

- For each child who applies to the program, the centers must complete and submit to DPH a worksheet listing the child's diagnostic category, immunization status, and level of acuity.
- Each quarter, they must submit a Statistical Report of Contract Activities, on which they report aggregate data on the children they serve, including demographic and geographic information; insurance coverage data; the number of clients served in group settings; the number receiving specific services, such as respite, educational consultation, and specific subspecialty services; and the number who were referred to and from specific sources.
- A family survey is conducted each year to assess each child's use of appropriate services and their families' satisfaction with the services their children receive and their role in managing their children's care.

The instruments used for this oversight system are included in Appendix B. However, no plans appear to be in place to replicate this system for children enrolled in HUSKY B Plus. In fact, despite the deliberate use of the Title V program as a model for HUSKY Plus, the DPH's Bureau of Community Health, which oversees Title V, has had only nominal involvement in the ongoing implementation of HUSKY. The Title V program's advisory group has become the Steering Committee for HUSKY Plus Physical, but Bureau staff do not track enrollment in HUSKY B, have not been extensively involved in outreach, and do not review data on HUSKY Plus. Thus, it appears that the state has not taken full advantage of the opportunity to build on the Title V CSHCN system or to benefit from the knowledge and experience of the program's staff in developing and monitoring the system of care for CSHCN.

III. Lessons Learned

In designing its SCHIP program, the state of Connecticut was firmly committed to a model that

was based on the state employees' benefit package and resembled a private-sector insurance product more closely than it did the Medicaid program. Moreover, to improve the image of Medicaid and help to assure complete coverage of uninsured children, the name of the Medicaid program was changed and the enrollment process simplified, changes that were reported to have been well received in the community. In fact, with HUSKY A enrolling three times as many enrollees as HUSKY B, one informant referred to SCHIP as "an expensive Medicaid outreach program."

The development of the HUSKY Plus program for children with special health care needs was also described as a necessary element in the strategy to avoid expanding Medicaid.

Policymakers were genuinely concerned about the burden and expense caused by children's chronic conditions, and wanted to avoid both expanding Medicaid to meet these children's complex needs and requiring families to spend large amounts out of pocket on uncovered services (and eventually spending down to Medicaid eligibility levels). In addition, the vocal advocacy of families and other organizations assured that the needs of CSHCN were not forgotten in the discussion of the SCHIP program. Therefore, HUSKY Plus was created to wrap around the HUSKY B benefit using the model of the Title V CSHCN program.

Most informants supported the model for serving CSHCN, at least in theory (although some would have preferred an expansion of Medicaid.) The major current challenge for the HUSKY program is to understand and address the relatively low number of children enrolled in HUSKY Plus. In discussing this issue with representatives of all aspects of the program, three hypotheses emerged to explain the program's results to date:

- **Hypothesis 1: Limited target population.** Several informants suggested that children with special health care needs are unlikely to be completely uninsured, and are thus ineligible for HUSKY B. These respondents reasoned that many families with severely disabled children are already covered by Medicaid or SSI, and that those with children ineligible for SSI would have done everything they could to get that child covered, even if they insure no one else in the family, and even if that insurance is expensive and incomplete. (While the six-month waiting period for children who were previously insured may be waived for reasons of financial hardship, the fact that insurance is inadequate to meet a child's needs is not one of the available exceptions.) Thus, under this theory, the state's estimate

that 8 percent of HUSKY B enrollees would be eligible for HUSKY Plus may be an overestimate, and the low number of children enrolled in the Plus program would not be unexpected.

- **Hypothesis 2: Inadequate outreach for HUSKY B.** The second explanation assumes that potentially eligible children do exist, but are not enrolling in HUSKY B. The lack of outreach efforts targeted to CSHCN, confusion about the program’s name, and the fact that it is run by DSS may all contribute to low enrollment in HUSKY B, particularly among CSHCN. (This hypothesis does not explain why enrollment in HUSKY A has been so much more successful.) Under this explanation, the low number of children enrolled in HUSKY Plus would be attributable to the low number enrolled in HUSKY B.

- **Hypothesis 3: Inadequate referral systems to HUSKY Plus.** The third theory attributes the low enrollment in HUSKY Plus to the systems used by managed care plans to identify and refer eligible CSHCN to the Plus programs. The use of limited diagnostic lists to define eligible children, the tendency of plans not to refer until a clinical service is needed, and the lack of a uniform way to operationalize the program’s definition of CSHCN may all have contributed to low rates of referrals to the Plus programs. This explanation addresses the low percentage of HUSKY B children enrolled in HUSKY Plus, rather than the absolute number of children enrolled in HUSKY B.

It is likely that a combination of these factors has contributed to the current enrollment situation. Table 1 compares the number of enrollees in each program to the number expected, based on HCFA’s estimates and state officials’ assumptions. As the table shows, the enrollment data demonstrate that enrollment in all of the HUSKY programs is lower than expected. HUSKY A has enrolled 23 percent of eligible children, while HUSKY B has enrolled 18 percent of its target population. Given that the program has been in existence only one year, these results are not necessarily unreasonable.

Table 1. Actual Versus Expected Enrollment in HUSKY Programs (July 1998-June 1999)			
Program	<i>Expected Enrollment</i>	<i>Actual Enrollment</i>	<i>Percent</i>
HUSKY A	53,000	12,000	22.6%
HUSKY B (Bands 1 & 2)	22,300	4,074	18.3%

Given the total enrollment numbers, however, the percentage of HUSKY B enrollees who go on to qualify for HUSKY B Plus remains much lower than expected. The HUSKY B Plus Physical program's 20 enrollees represent one-half of one percent of the total enrollment in the HUSKY B program, far lower than the 8 percent expected by state officials. In comparison, the Title V CSHCN program enrolled 3.1 percent of new HUSKY A enrollees during the same period, more than six times HUSKY B's yield. The HUSKY B Plus Behavioral program has enrolled an even smaller proportion of potential eligibles. Nevertheless, the numbers show that enrollment has been lower than anticipated in each program at each stage of the process.

Table 2. Expected Versus Actual Enrollment in Programs for CSHCN (July 1998-June 1999)				
Program	<i>Prevalence Assumption</i>	<i>Expected Enrollment</i>	<i>Actual Enrollment</i>	<i>Percent (actual/expected)</i>
Title V CSHCN/HUSKY A	8%	12,000	369	3.1%
Husky Plus Physical/HUSKY B	8%	4,074	20	0.5%
Husky Plus Behavioral/HUSKY B	2%	4,074	7	0.2%

Several suggestions emerged for increasing enrollment in the Plus programs. These included the following:

- **Up-front screening.** Several informants suggested that a mechanism was needed to identify CSHCN at enrollment, rather than waiting for referrals from the plans' Utilization Management departments or primary care providers. A brief series of questions on the application form, or during a plan's welcome call, might succeed in identifying a broader range of children who have special health care needs but who may not be easily identified through their claims. However, it was stressed that such questions must be prefaced by an assurance that the information was to be used to assure that children receive needed services and not to restrict access to care.
- **Clearer guidance.** The plans showed varying awareness of the breadth of the HUSKY Plus program's definition of CSHCN. One plan was under the

impression that only children with one of 11 diagnoses were eligible for the program, whatever the extent of their needs; another only referred to HUSKY Plus when the HUSKY B benefit limit was reached; and the third was aware that a broader criterion existed but did not know how to operationalize it. If referrals are to be made by the plans, it is evident that a clear, consistent system is needed to identify children who may be eligible for the program, using the type of diagnostic and utilization information generally available within a managed care organization.

Interviews with the HUSKY Plus contractors and the families of CSHCN underlined the importance of assuring that all eligible CSHCN, not just those who have exhausted their HUSKY B benefits, be enrolled in the Plus program. In addition to the clinical services financed by HUSKY Plus, the two contractors provide support services to children and their families that have proven to be critical in helping families to navigate managed care systems, coordinate medical services and educational services in the community, and provide access to the support of other families. These support services may be used and appreciated by any family with a chronically ill child, whether or not they have exhausted their HUSKY B benefits. The broad definition of CSHCN adopted by the program demonstrates the program's intent to serve these families, but it is evident that only those children with clinical service needs currently have access to the program.

Once enrolled in the program, children receive care through the systems of care developed by the Title V program for CSHCN. When the HUSKY plan was developed, this program had recently been reshaped through contracts with the state's two major children's hospital centers. This program's coverage wrapped around the Medicaid and private benefit packages, offering support services, additional therapies, and respite care (a recent addition). This program provided a successful model to form the basis for a wrap-around model of care for CSHCN under the new HUSKY B program.

This wrap-around approach appears to have both advantages and disadvantages. Because the HUSKY plans are responsible for both primary and specialty services for CSHCN, the model minimizes the incentive to refer children inappropriately to the Plus program to avoid their costs. In addition, the use of an established system to provide wrap-around services offers the

advantage of experience and the benefit of an established infrastructure that does not depend on HUSKY Plus funding for its existence.

The major disadvantage of this model is the complexity of its implementation. The plans' lack of understanding of the eligibility requirements and benefits of the Plus programs appears to be the major barrier to enrollment in the programs. In addition, the fiscal challenge of the wrap-around model is particularly apparent in the experience of the HUSKY Plus Behavioral program. While the provider agencies in the contractor's network are required to offer the services of both a Master's-level clinician and a paraprofessional, they cannot fund these positions with reimbursements from this program alone. This situation was described as a "management challenge;" in a community without other sources of funding for children's mental health services, it could be insurmountable.

Thus, while the HUSKY model includes many of the elements necessary for a comprehensive system of care for CSHCN, the issues lie in their implementation. Connecticut officials now face the challenges of fully operationalizing the intentions of their ambitious program and of communicating the program's details to the plans and providers on whom it depends.

Case Study: Florida

I. Background and Overview

Florida is recognized as a national leader in the development of public/private partnerships to provide subsidized health insurance for low-income children. Beginning in 1993, the Florida Healthy Kids Program was established to provide coverage to school-aged children in low-income families who do not qualify for Medicaid; this program was one of three set out as a national model and grandfathered into Title XXI. However, because Healthy Kids is aimed primarily at school-aged children, a significant population of low-income children between the ages of 1 and 5 years old remained uninsured. Therefore, Florida used Title XXI funds to expand Healthy Kids and Medicaid for children, while adding new programs in an attempt to cover uninsured children in Florida with family incomes at or below 200 percent of the Federal Poverty Level (FPL).

To this end, an umbrella program, entitled KidCare, was created, which consists of four components, as described below:

- Medicaid for children provides entitlement coverage to children from birth to age 1 with family incomes up to 185 percent of FPL, ages 1-5 up to 133 percent of FPL and children ages 6-19 with family incomes up to 100 percent of FPL.
- MediKids, a non-entitlement program, offers Medicaid benefits to non-Medicaid eligible children from birth to age 5 with family incomes up to 200 percent of FPL.
- Healthy Kids is a separate state program providing comprehensive coverage for the school-aged population (ages 6-18) and, in some cases, the younger siblings of enrolled children, with family incomes up to 200 percent of FPL. Healthy Kids operates on the county level, and is currently active in 58 of the state's 67 counties. Unlike the other programs, Healthy Kids is funded through a combination of state, federal, and local funds.
- Children's Medical Services (CMS) operates a statewide specialty network specifically for CSHCN. CMS is the administrative agency for both the Title V and the Title XXI CSHCN programs. A sub-component, the Behavioral Health

Specialty Care Network (BHSCN), provides services for children with serious emotional disturbance (SED) and substance abuse problems.

Florida's Title XXI program was authorized by the state in 1997 and approved by the Health Care Financing Administration (HCFA) in March 1998. The program has been implemented in two phases. In Phase One, implemented in April 1998, Title XXI expanded Medicaid coverage for children to ages 15-19, by raising the Medicaid income eligibility level for this group from 33 percent of FPL up to 100 percent of FPL. In addition, the existing Healthy Kids program (for school-aged children with family incomes up to 185 percent of FPL) was expanded to include additional counties. In Phase Two, an amendment to HCFA approved in September 1998 made the following changes to the program:

- The program was named Florida KidCare, uniting the four program components—a Medicaid expansion for children ages 15-19, MediKids, Healthy Kids and CMS;
- Coverage of school-aged children under the Healthy Kids program was expanded to those in families at or below 200 percent of FPL;
- MediKids, a new Medicaid-equivalent program for children not eligible for Medicaid, administered by the state Agency for Health Care Administration, was added;
- The CMS program was modified to include clinically eligible children in families with income at or below 200 percent of FPL.

A third phase of the program was planned to subsidize employer-sponsored dependent coverage for children from birth to age 19 with family incomes up to 200 percent of FPL. The amendment for Phase Three, which was submitted to HCFA in December 1998, generated considerable questions and requests for revision from HCFA. At the time of the site visit, the amendment had recently been denied by HCFA and the state had no plans to further revise its proposal.

No single agency is responsible for the administrative oversight of the KidCare program. Operation of the program components is a cooperative effort among several agencies, including the Agency for Health Care Administration (AHCA), the Florida Healthy Kids Corporation

(FHKC), the Department of Health (DOH), and the Department of Children and Families (DCF), as described below:

- AHCA manages the funding and monitors the KidCare program. It is also the administrative agency for the Medicaid and Medikids programs.
- DOH operates the CMS network, coordinates statewide outreach and chairs the Florida KidCare Coordinating Council.
- DCF is contracted by CMS to manage the Behavioral Health Specialty Care Network (BHSCN), and is responsible for Medicaid eligibility determination.
- FHKC, a state-chartered non-profit corporation, accepts and processes all KidCare applications and premiums and acts as the administrative agency for the Healthy Kids program.

Because no single administrative agency is responsible for all components of the KidCare program, a KidCare Coordinating Council, composed of 15 interagency groups mandated by the legislature and several groups appointed by the Secretary of Health, meets quarterly to coordinate program administration and address implementation issues.

The needs of CSHCN were brought to the forefront early in the state's Title XXI deliberations by advocates who were concerned that mainstream managed care plans would not have the necessary providers to meet the needs of CSHCN, limiting children's access to necessary care. Early discussions of this issue raised the idea of creating a wrap-around program for CSHCN, but there was concern that such an arrangement would consume too much of the Title XXI funds allowed for administration. The state also considered applying for a Medicaid 1115 waiver to allow CSHCN to be served through the Medicaid program; however, concern regarding cost derailed this idea as well. It was decided that a separate network designed especially to meet the needs of CSHCN, based on the existing CMS model, would effectively address the concerns related to this population. Moreover, officials of the Healthy Kids program were very supportive of moving CSHCN to the CMS Network as it would significantly lower the level of risk that their program had to accept.

The CMS Network provides CSHCN with comprehensive health care through a Medicaid benefit package, special care coordination services, preventive and early intervention services

and access to a network of contracted certified specialty providers. This model represents an extension of the approach in use for several years under Florida's MediPass system, the primary care case management (PCCM) program offered under the state Medicaid managed care initiative. Under this program, Medicaid-eligible children identified with special health care needs are exempt from enrollment in the state's capitated HMOs; instead, they enroll in MediPass, with their care provided through the CMS Network, which is operated by the state's Title V program. Under KidCare, the same system is used to serve CSHCN, but services are financed under a capitated rate rather than through fee-for-service payments.

Children with SED diagnoses or severe substance abuse problems are referred to a Behavioral Health Specialty Care Network (BHSCN) contracted by CMS and administered through the Department of Children and Families (DCF). The BHSCN was designed to ensure integration of physical and behavioral health care and meet the treatment needs of children with the most serious emotional disturbances or substance abuse problems.

In November 1999, we conducted a four-day site visit to gather further information about the Florida KidCare program and its services for children with special health care needs under Title XXI. During the site visit, interviews were conducted with representatives of the Agency for Health Care Administration, Florida Healthy Kids Corporations, CMS, the Department of Health, the Department of Children and Families, state legislative staff, providers and families of CSHCN. In addition, a telephone interview was conducted with a representative of the Institute for Child Health Policy.

This report presents an in-depth description of our findings. The following section describes issues related to the program's eligibility, enrollment, and outreach provisions; benefits and service delivery systems; financing and quality monitoring for CSHCN. The final section of the report provides an analysis of our findings and lessons learned from the program's first year of operation under the KidCare structure.

II. The Florida Model

A. Eligibility, Enrollment, and Outreach

As described above, the KidCare initiative comprises four program components, each with its own eligibility criteria:

- The Medicaid program for children expansion covers children ages 15-19 with family incomes below 100 percent of FPL.
- MediKids covers children birth to age 5, with family incomes below 200 percent of FPL.
- Healthy Kids covers children ages 5-18 with family incomes below 200 percent of the FPL. Younger siblings of enrolled children are also eligible for coverage in most counties. Enrollees must not be dependents of a state employee, eligible for Medicaid or covered under private insurance. Healthy Kids is a non-entitlement program; therefore, the number of slots available in each county is limited, and most counties have a waiting list for coverage.¹¹ In addition, Healthy Kids limits new enrollment to a specified “open enrollment period” each year to discourage families from waiting to enroll until their children need health care.
- CMS covers children under age 19 with family incomes below 200 percent of FPL and who have been determined to have a special health care need according to the state’s definition: a functional disability or condition expected to last 12 months which requires extra or special medical care, therapies, supplies or equipment.
- The Behavioral Health Specialty Care Network (BHSCN) provides enhanced coverage for children ages 5-18 who are identified as having SED or a substance dependence diagnosis. The program’s original eligibility criteria also provided for coverage of children diagnosed with childhood schizophrenia, bipolar disorder, or major depression. However, these criteria were determined to be too limiting, as many of these children would be eligible for SSI, and thus for Medicaid. Therefore, eligibility was expanded to include children who are enrolled in Title XXI and meet the following clinical *and* treatment criteria:
 - Clinical Criteria: The child must have: 1) projected utilization needs that exceed HMO benefits; 2) an allowable diagnosis, including a DSM-IV diagnosis or mood, psychotic, or anxiety disorder or substance

¹¹ The recent denial of the proposed employer-sponsored program will make additional funds available to expand the Healthy Kids program. These funds will soon be transferred to the Healthy Kids program to create new program slots.

dependence; *or* 3) significant functional impairment as measured by the Children's Global Assessment Scale, a SED school classification or commitment under the Marchman Act.

- Treatability Criteria: The child must not require long-term residential treatment (no more than 3 months); the child's family must be willing to participate in the treatment plan; and there must be reasonable expectation of significant improvement or stabilization of the condition.

Funding is currently available to serve a total of 303 children under this pilot program. These slots are distributed across the state's 15 districts. At the time of the site visit, three regions had filled their slots, and the other 12 were just beginning enrollment.

Applications for all of these programs are initially sent to the Healthy Kids Corporation, where eligibility workers screen applicants for Title XXI eligibility and forward applications to Medicaid when appropriate. To expedite this process, several Medicaid eligibility workers have been stationed at the Healthy Kids central office. This system allows the state to use a single application form for all KidCare programs. The major disadvantage of this system is that the Healthy Kids eligibility staff, as the single point of entry for four programs, became considerably backlogged soon after this system was instituted, causing significant delays in getting families enrolled in KidCare; as many as 2,000 applications were backlogged in early 1999. The backlogs were due in part to the large influx of applications generated by statewide outreach activities, overloading the application processing system early in the program. (Indeed, one parent interviewed reported that she got a letter confirming the receipt of her application in October 1999, four months after she sent in her child's application, and by November she had still not received a membership card.) The increase in volume of applications received also resulted in the formation of long wait lists for Healthy Kids enrollment in some counties which were already at maximum capacity.

The KidCare application identifies CSHCN by asking if the child has a medical or developmental condition expected to last more than twelve months. When an applicant indicates that their child has a special need, the application is referred from FHKC to the CMS office in the child's region. Concurrently with FHKC's determination of the child's financial eligibility for Title XXI, CMS case managers will review the application to determine whether

the child meets the CMS functional and diagnostic criteria. If a determination cannot be made by a telephone interview, a medical consultation is conducted and the final CMS eligibility decision is made by the CMS medical director. If the child is financially eligible for Title XXI and determined to be clinically eligible for CMS, the child will be enrolled in the CMS Network.

If denied for CMS, the application is returned to FHKC and reviewed for Healthy Kids or MediKids eligibility. Applicants who are financially eligible for Medicaid, but clinically eligible for CMS, are enrolled in Medicaid, but may use the CMS Network. The family must, however, actively choose CMS as their plan rather than the Medicaid HMO or MediPass options. Although Medicaid's enrollment contractor provides counseling to help families choose the plan that best fits their needs, they do not always remind families of CSHCN to choose the CMS network.

The Behavioral Health Specialty Care Network (BHSCN), which is administered by the Department of Children and Families under contract to CMS, uses its own screening and assessment process to determine clinical eligibility. Because the screening question on the application does not ask about mental or behavioral health needs, very few applications submitted to FHKC indicate a need for behavioral health care; most referrals for the behavioral health program are generated through CMS or through outreach by the Behavioral Health Liaison in each county. Once a referral has been made, a behavioral health assessment is completed. If the child is eligible for BHSCN, the enrollment forms are forwarded to CMS for potential enrollment; children cannot begin receiving services through BHSCN until enrolled in the Title XXI component of KidCare and placed in BHSCN by CMS.

Because the CSHCN screening question on the application is so broad, it has succeeded in identifying children with needs ranging from eyeglasses to ongoing rehabilitative care. On the other hand, regional CMS staff indicated that some parents seem to misunderstand the screening question because they do not perceive the care their child needs as 'extra' or 'special.' In the first year of the program, over 30,000 applications, or nearly one third of all applications received, were referred to CMS as a result of the special needs question, but only 40 percent of these were found to be CMS-eligible upon screening. Each of the 22 local CMS offices has

created a full-time member services unit to handle the high volume of applications that are now forwarded for screening. The behavioral health network faces a similar predicament; the majority of referrals received from CMS are not clinically eligible for BSCHN.

Upon enrollment, participants in Healthy Kids, MediKids and the CMS Network are required to contribute to the cost of their children's insurance premium. Families are required to pay \$15 per month and participants are disenrolled if the payment is late. Once disenrolled, the child is ineligible for participation in the program for 60 days. The suspension period was instituted to limit adverse selection—that is, to discourage families with ill children from participating in the program only when they need specific and particularly expensive health care services.

Interviewees at a local health department and CMS clinic indicated that the lack of a grace period for late payment and the 60-day wait period causes many families, for whom socioeconomic factors make it difficult to send in consistent timely payments, to cycle in and out of insurance coverage throughout the year.

Florida has not instituted provisions specifically to deter crowd-out, meaning that there are no waiting periods or other mechanisms in place to dissuade families from dropping their current coverage and applying for KidCare coverage. Medicaid representatives indicated that, in Florida, much of the population works for businesses that have fewer than 50 employees, and few of these employers offer dependent health insurance coverage. Therefore, it is unlikely that significant numbers of parents or employers would be tempted to drop coverage to enroll in the Title XXI program. Preliminary data collected by Florida's Institute for Child Health Policy (IHP) indicate that nearly 80 percent of children in KidCare had no insurance or access to insurance in the year prior to enrollment and nearly 90 percent had no employer-based coverage in the year prior to enrollment. Study participants were unanimous in their opinion that crowd-out is not an issue in the state.

Backlogs in processing applications and long wait lists for counties that have filled their local service capacity are also serving as an unintended deterrent to crowd-out, since KidCare-eligible families are likely to be faced with several months without coverage between the time they submit an application to FHKC and the time they are actually enrolled in the program. CMS

administrators indicated that regional CMS staff encourage under-insured families *not* to drop their current coverage because it takes a while to get enrolled in the Title XXI program, so they will be left uncovered for a period of time.

The Department of Health (DOH) is charged with developing statewide outreach strategies. They have conducted numerous outreach activities for the overall KidCare program on both a statewide and regional level, including the following:

- Training workshops conducted to increase understanding of the program for policymakers, providers, community partners and local agencies;
- Statewide bilingual multimedia (TV and radio) program promotions;
- Multilingual direct mail campaigns;
- Program information distributed to school districts;
- A KidCare Internet site made available to the public in three languages; and
- A family advocacy outreach program developed to assist families with unresolved questions or problems related to KidCare.

Outreach activities are also conducted through the Covering Kids Grant administered by University of Southern Florida in collaboration with DOH and AHCA. Covering Kids outreach activities have included a family survey regarding the effectiveness of state outreach activities, market research on why parents do or do not enroll in the program, and the production of a statewide instructional video teleconference for community-based enrollment staff.

The DOH and Covering Kids outreach efforts are targeted toward the KidCare population generally, and do not include outreach specifically for CSHCN. Outreach for CSHCN is conducted primarily by CMS, which conducts outreach activities through local committees at the district level. CMS also works with the Healthy Kids plans to identify high users of acute care services who may be eligible for the CMS Network. If the family does not indicate on the initial KidCare application that a child has a special need, they may remain unidentified in the KidCare system unless they become a high utilizer of services. When identified and eligible, these children are transferred from Healthy Kids to the CMS network. CMS staff indicated that

nearly 1,000 children have been transferred from Healthy Kids to CMS.

CMS outreach activities have also targeted families who previously received CMS services at no cost under the Title V program, but are now eligible for CMS under the Title XXI KidCare program. The state mandated that eligible families be ‘converted’ to Title XXI CMS or be disenrolled from CMS. CMS case managers have made phone calls and home visits to urge families to transfer to Title XXI, but have had limited success; because these families are accustomed to receiving CMS services at no cost, they do not always understand the value of enrolling in a program for which they must contribute \$15 a month. CMS workers indicated that they are exploring the viability of establishing a system with a privately-funded charitable organization which would temporarily fund premiums for families who have difficulty paying so that they do not lose CMS coverage.

Outreach strategies for the Behavioral Health Specialty Care Network (BHSCN) are just beginning to be developed. Prior to Title XXI, the Department for Children and Families (DCF) had limited capacity to provide behavioral health services to children; therefore, no outreach was conducted. Outreach is now being conducted to identify children for the 303 BHSCN slots. A Behavioral Health Liaison in each district is responsible for conducting outreach activities, which have included presentations to community organizations and agencies, information dissemination at conferences, and trainings. These liaisons also coordinate outreach activities with the Department of Education/Department of Health’s SENET program, an initiative to coordinate services at the local level for SED children.

Outreach efforts have led to the enrollment of 150 children into the BHSCN in its first year of operation. This is nearly half of the 303 allocated behavioral health slots in the state, although the program was only fully operational in 3 districts at the time of the site visit. The total population of SED children in school settings is 6,000, but the proportion of those children who are uninsured and have family incomes between 100 and 200 percent of FPL is unknown; therefore, the total population of eligibles for the behavioral program is also unknown. At the time of the site visit, CMS had been successful in enrolling 3,000 of the 60,000 children

estimated to be eligible for the program.¹²

An estimated 823,000 children in Florida are uninsured, representing 23 percent of children in the state.¹³ Nearly 294,000 of these children are eligible for Medicaid but not enrolled and 259,000 were estimated to be within the Title XXI income range. As of November 1999, Healthy Kids had enrolled 117,013 children, nearly half of the number estimated to be eligible. Study participants indicated that many more children have applied and are currently wait-listed because the currently appropriated slots are filled. Program administrators are hoping the legislature will soon appropriate funding for the additional 86,000 slots needed to accommodate these families.

B. Benefits

With the exception of the Healthy Kids program, all of the Florida KidCare program components offer enrollees the full Medicaid benefit package. The Healthy Kids benefit package, which was grandfathered into Title XXI, includes comprehensive inpatient, outpatient and surgical services, prescription drugs, laboratory and radiologic services, prenatal care and pre-pregnancy family services and supplies, home and community-based health care services, disposable medical supplies and nursing care services. Limited psychiatric, rehabilitative and physical therapies; alcohol and drug services; chiropractic and podiatric services; durable medical equipment (DME) and remedial devices are provided. Dental services may be covered at the discretion of the county.

As discussed below, the CMS and BHSCN benefit packages are based on Medicaid's EPSDT benefits. However, the benefits offered through these programs are, in some circumstances,

¹² Estimates of the CMS-eligible population were based on national estimates of uninsured disabled children below 200 percent of the FPL as discussed by Paul Newacheck in "Children with disabilities under the state children's health insurance program." Maternal and Child Health Policy Research Center. December 1997.

¹³ Institute for Child Health Policy. Preliminary Report - Florida KidCare. March 1999. This estimate is based on CPS data, however, State-specific estimates of uninsured children are currently being developed by the University of Florida.

richer than Medicaid's, as described below:

- CMS provides the Medicaid package and other services that are medically necessary, including early intervention, respite, genetic testing, genetic and nutritional counseling, parent support and care coordination. CMS also covers services that Medicaid has not traditionally paid for, such as nursing care and certain types of equipment and supplies, although these services might technically be covered under EPSDT's treatment provision. The primary care physician is responsible for approving services based on medical necessity criteria. Mental health services, however, are limited to 40 outpatient and 30 inpatient visits annually. Enrollees are referred to BHSCN if additional services are required and slots are available in the area.
- BHSCN provides all of the behavioral health benefits available to Medicaid enrollees as medically necessary, plus an assortment of enhancements such as individualized wrap-around services, intensive case management, respite care, and other support services. Services covered without specific utilization limits are: inpatient services, treatment planning, clinic visits, evaluation and testing services, day treatment, home and community rehabilitative services and pharmaceutical services. Services must, however, be approved through an authorization process. In addition, BHSCN enrollees are enrolled in CMS for their physical health care and have access to the full CMS benefit package.

Regional CMS staff pointed out that, although the benefit package is very comprehensive, access to the benefits is sometimes limited by a lack of providers, particularly for dental and vision benefits.

Care coordination, which is included in both the CMS and BHSC Networks, is a vital benefit for CSHCN, given the variety of services and providers that they are likely to need. One parent of a child enrolled in CMS indicated that even if she had the opportunity to enroll in a private insurance program that provided for the medical needs of her child, she would remain with CMS because of the invaluable services of the case manager. CMS Case Managers are usually registered nurses or social workers, and their case management style ranges from a medically-oriented approach to a more sociomedical team approach. The case managers at one CMS regional office indicated that the range of services they provide includes finding providers and transportation to medical appointments, counseling parents, making referrals to social services, setting up linkages with schools and, most of all, doing "detective work" to link enrolled families to the services they need. Similarly, Behavioral Health Care Coordinators coordinate

the child's behavioral and medical care and sociomedical needs and Behavioral Health Liaisons are also on staff in each district to provide coordination between BHSCN, the CMS Network and the primary care providers.

C. Service Delivery System

As with other aspects of KidCare, service delivery systems vary across the components of the program. MediKids and Medicaid enrollees are served through the Medicaid managed care system, in which enrollees choose between the Medicaid HMO or MediPass program and use Medicaid providers. The Medicaid provider network, however, is limited in some areas of the state and access to services such as vision and dental care, as well as some special services, is restricted by availability of providers. MediKids and Medicaid enrollees with CMS-eligible conditions may take advantage of the specialty network if they choose CMS as their plan.

Healthy Kids enrollees are served by commercially licensed health plans selected through a competitive bid process. Each county is responsible for contracting with at least one health plan to serve their Healthy Kids enrollees, and some counties have contracted with two plans to increase the program's capacity.

CMS enrollees are served through a network of providers, including primary care providers, specialists, hospitals, DME suppliers, and therapists, developed specifically for CMS through a credentialing process. CMS conducts its own credentialing for all providers and credentials are reviewed annually. For example, physicians are required to be board certified, have hospital privileges and malpractice insurance, and have no history of sanctions against them in order to be placed on the CMS panel of providers. At the state level, CMS oversees contracts, network policy and program planning, as well as specialty program development and quality assessment. At the regional level, twenty-two area offices are responsible for providing case management, selecting providers, processing credentialing packages, purchasing services, and managing local administration of the CMS Network which allows the program to be as responsive as possible to the needs of local enrollees.

The Behavioral Health Specialty Care Network allows the behavioral health care of children with the most severe mental health needs to be provided outside of the main CMS system, but CMS is the medical home for all BHSCN enrollees. As mentioned above, current state appropriations have limited the BHSCN capacity to 303 slots divided among 15 participating districts, and only three were fully operational at the time of the site visit. Each district negotiates risk-bearing contracts with a lead agency, usually a community mental health center. Although the contract requires the lead agency to assume responsibility for providing all BHSCN services, they are permitted to, and often do, subcontract with other community-based providers to provide the full array of covered services. Alternatively, some districts contract with agencies for specific services rather than using a central lead agency. BHSCN administrators indicated that they have had no difficulty identifying providers for the network because of the existing network of providers available through the Children's Mental Health Program Office. The BHSC program had only to provide incentives for the existing providers to join together into service networks.

D. Payment

All of the KidCare programs are funded on a capitated basis. However, the methodologies used to develop the rates and the rates themselves vary across the four programs. In the capitated managed care system set up by the Healthy Kids program, capitation rates for the plans are set through a negotiated bidding process with each plan. The rates range from \$75 to \$91 per child per month and are not age-adjusted. Rates paid to the plans have increased over the life of the program, although the risk borne by the plans has decreased since CSHCN were moved to the CMS and BHSC Networks. This rate increase has been reported to be instrumental in retaining physicians and developing networks in some rural areas of the state. The service capacity of the Healthy Kids program in each county is limited by the number of state-appropriated slots and the local match generated by the county.

CMS receives an age-adjusted monthly payment from the state for each enrollee: \$3,276 per child under age 1; \$557 for each child ages 1 to 4; and \$474 per child 5 to 17 years old. Under the current contract arrangements, CMS at the state level assumes full risk; however, CMS is

considering the possibility of providing capitated payments to networks of CMS providers in the future. This approach would transfer risk to the regional level, an even riskier arrangement, as risk would be spread across a smaller population of children, all of whom may need high-cost care. Some providers, such as Shands Hospital in Gainesville (an affiliate of the University of Florida), are considering taking on this risk. However, state officials are concerned that those who use fewer services may drop out of the program while high users remain, raising concerns regarding contractors' ability to cover the risk in the future.

CMS providers are paid on a fee-for-service basis at Medicaid rates, with no adjustment for the cost of caring for high-need children. Low payment rates may be, in part, responsible for the difficulty CMS has had in contracting providers in some areas of the state, particularly given that Medicaid rates in Florida have not been increased in 10 years and were referred to by study participants as being "abominably low."

CMS receives an additional flat rate of \$1441.77 per BSCHN enrollee per month. These funds are forwarded to the ACF central office, which in turn pays a capitated rate to the lead agency in each district. The lead agencies are protected by a 15 percent risk corridor.

E. Quality Monitoring and Oversight

As is the case in many states, early program efforts have focused primarily on start-up activities and enrollment; monitoring and evaluation mechanisms are just now beginning to gain more attention. The state Title XXI legislation mandates systematic data collection from all KidCare systems partners, and data are being collected on different aspects of the program from a variety of sources:

- The Institute for Child Health Policy (ICHP), an affiliate of the state university system, was contracted to track the number of children ever enrolled and point in time case-loads and analyze utilization data. Utilization reports are generated biannually by ICHP. The plans are alerted to follow up on utilization trends.
- FHKC and its third party administrator submit data to ICHP regarding each KidCare applicant, the length of time the application was in process, and eligibility outcomes.

- The University of Florida was contracted to survey families throughout the state to assess families' knowledge about the program and their source of information.
- Calls to the 800 information line are being tracked for demographic information and relationship to outreach activities.
- Focus groups have been conducted with hard-to-reach populations.

The overall focus of the CMS monitoring activities is assessing the cost-effectiveness of operating a special network for CSHCN. CMS has identified several quality indicators: 1) well-child supervision (EPSDT); 2) immunization compliance; and 3) families' perception of care. The Institute for Child Health Policy, under a grant from the Federal Maternal and Child Health Bureau, is working in partnership with providers to conduct a survey of CMS families' perceptions of care and analyze data related to inpatient/outpatient utilization, enrollment/disenrollment and client satisfaction. Once this pilot study has been completed, CMS will continue to monitor these indicators.

The Behavioral Health Specialty Care Network is just beginning to develop quality measures and monitoring standards, based on national best practices. As part of their quality assurance efforts, written procedures, a provider manual and family handbook are being developed with input from Family Voices, a CSHCN advocacy organization. Although planned for inclusion in the future, data on BSHC Network have not been included in much of the statewide data analyses as yet because of the small enrollment numbers in the network.

III. Lessons Learned

Study participants agreed that the health care system developed for Florida's low-income uninsured children is quite comprehensive, with excellent benefits for both the typical and special needs child, with the exception of dental coverage, which is not covered under Healthy Kids in many counties. The system is, however, very complex from both an administrative and consumer perspective. In a system with four separate program components under one umbrella, without a single agency assigned administrative control, coordination between program components is critical to facilitate access to and utilization of all program components.

This issue is particularly important for families who have children enrolled in more than one program component. Local program staff indicated that the separate program components are confusing for families and that some families are dissatisfied with the program because of the difficulties they have encountered related to differences in eligibility, services covered and networks among the components. A client satisfaction survey conducted by the ICHP, however, did not capture this perception among families who had children enrolled in multiple components; client satisfaction was not significantly lower among families who had children utilizing different KidCare program components.

Another side effect of the four-program structure is the problem it creates for outreach. While the state's outreach materials promote KidCare as a single program, this creates demand for the Healthy Kids program, which has enrollment caps and waiting lists in many counties. When people respond to outreach campaigns and hear that coverage is not available for their children, they lose faith in the system as a whole. However, the single "KidCare" program identity is considered to be critical to tie the program's disparate components together.

Issues regarding KidCare's cost-sharing requirements were also raised by study participants. Some informants, including legislative staff, indicated that Healthy Kids parents "feel good" about the premium because it allows them to feel like they are buying health insurance for their children as opposed to taking a hand-out from the state. Community-level interviewees, however, indicated that the premium is looked upon as an inconvenience, and in many cases a hardship, by parents. As discussed earlier, the premiums have created difficulty for local CMS staff who have had to convince parents receiving the CMS services for free under the Title V safety net program to pay for those same services under Title XXI. Not surprisingly, the number of eligible children 'converted' from the safety net program to Title XXI CMS has been lower than anticipated.

Identifying KidCare applicants who have special health care needs and getting them enrolled continues to be a challenge for the program. The current question on the application ("Does the child have a medical or developmental condition expected to last more than twelve months?") was felt by many interviewees to be too general; moreover, the question does not identify

children with behavioral issues at all.

Overall enrollment in the CMS program has been lower than expected, but study participants speculated that this is because there were no hard data upon which to base initial estimates of children who would be eligible for CMS under Title XXI. The state's estimate was based on a national estimates that 5 percent of the population of children could be expected to have a moderate to severe condition that would require specialty care. Among the children enrolled, utilization of services has been lower than expected. CMS children have, thus far, used primary care services much more heavily than specialty services, and these early utilization patterns have raised concerns among some observers regarding the need for a specialty network for CSHCN. However, representatives of Florida's ICHP predict, based on national trends and their experience tracking health care utilization, that utilization will increase over the life of the program.

To address many of the KidCare program's operational issues, the KidCare Coordinating Council is considering a wide range of potential recommendations for the legislature. As of November 1999, the policy issues under consideration by the Council included:

- Consolidation of administration of programs and funding under one KidCare agency;
- Reduction of the Healthy Kids local match;
- Removal of enrollment caps for KidCare programs;
- Removal or reduction of the 60 day cancellation period for failure to pay premium in Title XXI programs; and
- Inclusion of dental health benefits in the Florida KidCare benefit package.

Several recommendations related specifically to improvements for CSHCN:

- Implementation of an income disregard to allow families of CSHCN to deduct the cost of medical care from their incomes for the purpose of KidCare financial eligibility;
- Removal of the 60 day penalty for non-payment of premium or elimination of the premium for CSHCN;
- Presumptive eligibility for children with special and behavioral health care needs;

and

- Special capitation rates for autism services similar to specialty behavioral health capitation rate.

Finally, it is important to note that Florida's success in developing the CMS Network model under Title XXI is largely due to its experience implementing this system under the MediPass system. The CMS Network was built on partnerships between Title V and Medicaid that have been developed over many years, and the state had developed a considerable claims database on which to base its capitation rates for this population. Other states attempting to create a similar system might find the development of provider networks and capitation rates more challenging.

Case Study: North Carolina

I. Background and Overview

The development of the North Carolina SCHIP program is a story of both collaboration and partisanship. Prior to the passage of Title XXI, many state public health agencies, insurers, physicians and advocates were working together to develop a children's health insurance program in response to a Robert Wood Johnson Foundation Covering Kids grant. After the passage of the Balanced Budget Act of 1997, the Secretary of the North Carolina Department of Health and Human Services charged this group with developing recommendations for the design of North Carolina's SCHIP program. Co-chaired by the state Children with Special Health Care Needs Director and the President of the North Carolina Institute of Medicine, the group quickly grew from 15 to 60 members and represented various constituencies. In November 1997, the Task Force submitted policy options and recommendations to Governor Hunt.

After reviewing the Task Force report, the Governor recommended a Medicaid expansion to the General Assembly. In February 1998, Governor Hunt called a two-day special legislative session to craft the state's SCHIP program. However, because the Assembly's two houses were controlled by different parties, consensus was not easily reached; while one house supported a Medicaid expansion for its rich benefits package, the other did not, because they did not want to create an entitlement program and did not want to burden counties with having to provide matching funds. While some providers supported a Medicaid expansion, others were in favor of a separate state program.

Just as it appeared that the two houses had reached an impasse, a compromise was struck. Both parties agreed that the SCHIP program would be based on the State Employees Health Plan. This was an attractive alternative, as the SEHP is overseen by the General Assembly, granting an additional layer of legislative control. Task Force members were pleased because

they were able to get a comprehensive benefit package after all; vision, dental, and hearing benefits were added to the core benefit available through the SEHP, as was a supplemental benefit package for CSHCN.

N.C. Health Choice for Children was implemented beginning 1 October 1998. Health Choice provides health insurance coverage to uninsured North Carolina residents under age 19 with family incomes below 200 percent of the FPL. This program provides access to health insurance for children with family incomes above the state's Medicaid limits, which are set at 185 percent of FPL for infants, 133 percent of FPL for children ages 1 through 5, and 100 percent of FPL for children ages 6 through 20.

The program's benefits parallel those provided through the State Employee Health Plan (SEHP)—The North Carolina Teachers' and State Employees' Comprehensive Major Medical Plan—plus additional dental, vision, and hearing benefits. Health services can be delivered by any provider in the state and are reimbursed on a fee-for-service basis. Described as a “three-legged stool,” the following agencies are responsible for different administrative components of the program.

- The Division of Medical Assistance (DMA) within the North Carolina Department of Health and Human Services created and submitted the SCHIP plan. DMA is responsible for the overall administration of the program, quality assurance, and directly oversees the county Departments of Social Service (DSS) responsible for Health Choice eligibility and enrollment.
- The State Employees Health Plan is responsible for Health Choice benefit administration and claims processing. The SEHP has contracted with BC/BS to serve as the third party administrator, a role they have played for nearly ten years with the SEHP. BC/BS reviews requests for prior approvals, processes claims and reimburses providers.
- The Children and Youth Branch (CYB) of the Division of Public Health's Women's and Children's Health Section, is responsible for conducting outreach for Health Choice.

In addition to services available through the core Health Choice benefit package, children with special health care needs (CSHCN) are eligible for additional Medicaid-equivalent physical, developmental, and mental health benefits that are not covered under the SEHP. Therefore,

North Carolina’s SCHIP program represents a wrap-around model for physical, developmental, and mental health benefits. These additional benefits are supported by a special fund combining roughly \$15 million in Title XXI and state matching funds. The enabling legislation further specified that case management and emergency respite care benefits, two services not currently covered by Medicaid, be made available to CSHCN. A few additional agencies and groups play a role in assuring access to and quality of care for CSHCN enrolled in Health Choice.

- The Division of Public Health not only handles outreach for Health Choice, but also provides oversight on policies related to CSHCN and administers the additional wraparound benefits. As the agency responsible for the Title V CSHCN program in North Carolina, DPH and the CYB, in particular, was perceived as a natural partner for DMA when developing special provisions for CSHCN in Health Choice.¹⁴
- ValueOptions, a behavioral health administrative service agency, is contracted by BC/BS to manage mental health and substance abuse services. DPH also contracts with ValueOptions to manage respite care services, as well as services for children with developmental disabilities. Finally, ValueOptions is responsible for determining when the wraparound behavioral health benefits for CSHCN should be utilized.
- The North Carolina Commission on Children with Special Needs was created by state statute to monitor access and quality of services for CSHCN under SCHIP. The Governor appointed several members to serve on the Commission, including two parents of CSHCN, a psychologist, a psychiatrist, a pediatrician who serves CSHCN, a children’s hospital representative, a director of a local health department, and a provider of special education services. The DPH provides staff support for the Commission.
- The Behavioral Health Work Team was also formed to help shape policy with respect to CSHCN. Among others, representation includes members from the

¹⁴ The Title V CSHCN program in North Carolina has embraced a systems development model for serving CSHCN. Over a period of many years, the Children’s Special Health Services (CSHS) program has reduced the number and scope of direct services it provides, and instead carries out activities related to the core public health functions—assessment, policymaking, and assurance. However, the CSHS program has continued to operate 18 Developmental Evaluation Centers and 18 Speech and Hearing Teams statewide, as the private sector does not meet the needs of CSHCN in these areas. The CSHS also supports case management services provided through Child Service Coordinators housed in local health departments. Unlike many other states, North Carolina’s Title V CSHCN program is not directly linked to eligibility or service provision for CSHCN enrolled in SCHIP. However, the state-level staff who administer the CSHS program played a key role in designing the SCHIP CSHCN provisions, oversee outreach and benefits education, and participate in the administration of the wraparound benefit package for CSHCN enrolled in Health Choice.

state Division of Mental Health, ValueOptions, the North Carolina Psychiatric Association, Area Mental Health Agencies, Developmental Disabilities, and the SEHP. Two of these members also serve on the Commission.

We conducted a three-day site visit in September 1999 to gather information on the Health Choice program and its provisions for CSHCN. During the site visit, we interviewed representatives of CYB, DMA, SEHP, the Commission on Children with Special Needs, BC/BS, ValueOptions, a Title V CSHCN Speech and Hearing Clinic and Developmental Evaluation Center, and members of the Title V Parent Advisory Committee. Additional interviews were conducted by telephone with Family Voices, North Carolina Child Advocacy Institute, North Carolina Health Access Coalition, and the Riverstone Area Mental Health Program. Telephone interviews were also conducted with several families of CSHCN who are enrolled in Health Choice.

This report presents a detailed description of our findings. The following sections will address in greater detail issues related to eligibility, enrollment, and outreach; the benefit package; the service delivery system; financing arrangements; and quality monitoring for CSHCN. The final section of this report discusses some of the lessons learned from the program's first year of implementation.

II. The North Carolina Model

A. Eligibility, Enrollment, and Outreach

To be eligible for Health Choice, children must not be eligible for Medicaid, must reside in the state, be uninsured for two months, and have family incomes below 200 percent of the FPL. Applicants must submit one month's worth of pay stubs or, if self-employed, one year's worth of business records. Deductions are taken for child care costs and work-related expenses when calculating family income. Beginning 1 October 1999, those who were previously enrolled in the program whose family incomes increase from 200 to 225 percent of the FPL, may elect to purchase coverage at full cost for one year.

To deter crowd out, North Carolina implemented a waiting period, meaning that children who are otherwise eligible may not apply for the program if they have had insurance coverage during a specified period of time. For the first six months of the program, the legislation required that children be uninsured for six months. After this initial time period, the waiting period was reduced to 60 days. There are, however, some circumstances under which the waiting period can be waived:

- The child loses Medicaid coverage because of an increase in family income;
- The child loses employer-sponsored coverage when the parent loses a job;
- The parent's employer ceases to offer coverage; or
- The parent's employer goes out of business.

Using data from the 1995-6 Current Population Survey and state Medicaid data, officials estimated there to be roughly 138,300 uninsured children in North Carolina with family incomes below 200 percent of the FPL. Approximately 67,000 of these children were estimated to be Medicaid-eligible, and 71,300 were thought to be eligible for Health Choice. By mid-September 1999, 51,000 of the estimated 71,300 eligible children had been enrolled—far more than officials had projected. However, the outreach program had produced only approximately 17,000 new Medicaid enrollees. This may reflect a positive reaction to the BC/BS product, which more closely resembles private insurance, as well as a negative response to Medicaid.

County Departments of Social Service (DSS) serve as the single point of entry into Medicaid and Health Choice. North Carolina developed a simplified, combined application for Health Check, Medicaid's EPSDT program, and Health Choice. Counties have the authority to determine where and how broadly to distribute Health Choice applications; some counties distribute applications at provider sites, hospitals, child care centers, grocery stores, and fast food restaurants, while other counties prefer to keep a shorter rein on application distribution to reduce the number of incomplete applications submitted. The two-page application, which is available in English and Spanish, can be submitted in person at county DSS offices and local health departments, or it may be mailed to DSS offices. Eligibility workers screen families for eligibility in both Medicaid and Health Choice. If deemed eligible for Health Choice, families are sent a Health Choice card and a benefits booklet.

Because the Health Choice application does not identify CSHCN, the state had to develop alternative mechanisms for identifying CSHCN enrolled in the program.

- First, DPH created a five-item screening form to identify CSHCN from among those children enrolled in Health Choice. This one-page form, which was based loosely on the Questionnaire for Identifying Children with Chronic Conditions, is included in the Health Choice Handbook sent to all enrollees with their insurance card. Parents are instructed to call the Special Needs Helpline if they answer “yes” to any one of the five questions. These questions were designed to be broad and inclusive, to encompass children with birth defects, developmental delays, behavioral problems, and chronic physical conditions. The CSHC Helpline was expanded to provide families with information for CSHCN on Health Choice and to provide referrals to resources and services across the state.
- To estimate the *number* of CSHCN served through Health Choice and the cost of these services, DPH and BC/BS developed an identification system using paid claims data. DPH program staff compiled a list of ICD-9 codes in order to operationalize the intentionally broad definition of CSHCN set out in the North Carolina SCHIP legislation. They then created a special report to identify the number of Health Choice enrollees with a diagnosis who had received services and the costs of these services. From 1 October 1998 to 30 June 1999, Health Choice provided services to 4,057 CSHCN at a cost of roughly \$3.5 million.
- Finally, a prior approval process has been put in place to determine when the special fund for CSHCN should be utilized. This is yet another mechanism for program officials to identify CSHCN.

DPH was chosen to develop and implement SCHIP outreach strategies largely due to their proven track record with designing successful outreach initiatives for programs like Health Check and Baby Love, North Carolina’s maternity care coordination program. The DMA and the Health Choice Statewide Outreach Committee assist DPH in planning and implementing outreach activities, which are supported by a \$500,000 allocation from DMA. DPH allocated \$200,000 of this budget to local outreach and another \$200,000 was contracted out to the Healthy Start Foundation to develop outreach materials and a media campaign and to supplement the NC Family Health Resource Line.

The cornerstone of the Health Choice outreach strategy is the community development model—one with a successful history in North Carolina. The majority of Health Choice outreach is implemented through 100 county coalitions, many of which have been operating for

a number of years and were instrumental in Governor Hunt's popular *Smart Start* child development initiative. Under this model, local coalitions are autonomous in the design of Health Choice outreach activities in the communities. Several months after Health Choice was implemented, the state launched a geographically-targeted media campaign that was intended to build upon the grassroots foundation laid by the county coalitions. In May and June of 1999, the state ran English and Spanish television ads in Raleigh, Greensboro, and Charlotte, three urban markets where enrollment numbers were lagging. English and Spanish radio ads were also placed on 90 stations throughout the state, many of them in Eastern, rural North Carolina where enrollment was low.

All the outreach conducted by DPH and the county coalitions targets the general population of eligibles; no outreach materials have been developed specifically for CSHCN. However, DPH is currently developing a Health Choice Booklet for CSHCN, which includes information related to the additional wraparound benefits, prior approval procedures, providers, payment, and appeals. When finalized, DPH plans to send the booklet to families who call the Special Needs Helpline, and possibly to those who have had a claim paid for a diagnosis that falls within the state's definition of CSHCN.

B. Benefits

Health Choice enrollees are eligible to receive the same benefits provided to those covered by the SEHP, plus additional dental, vision, and hearing benefits, which were designed during the SCHIP legislative process. In addition to case management and emergency respite care, CSHCN enrolled in Health Choice also have access to Medicaid-equivalent benefits for physical and mental health. The general consensus of those interviewed for the case study was that the Health Choice benefit package is extremely generous. One case study participant claimed the Health Choice benefit package was "soup to nuts the best plan," as it contains components not covered by Medicaid or the regular SEHP.

Though the benefits are thought to reflect the best of Medicaid and private coverage, the Health Choice benefits diverge significantly from Medicaid in some areas, particularly for services most

often utilized by adolescents.

- **Transportation.** Medicaid provides county DSS office with funding for transportation, but Health Choice does not.
- **Prenatal Care.** Health Choice does not cover prenatal care, as the SEHP does not cover pregnant dependents. However, most advocates and program officials believe that because pregnant adolescents can qualify for Medicaid as a family of two, this coverage deficiency does not actually serve as a barrier to care.
- **Family Planning.** The SEHP does not cover family planning services as a specifically identified service; however, many family planning consultations take place within the context of a preventive health visit, which are reimbursable under Health Choice. Contraceptive supplies are covered.
- **Preventive Health Visits.** For children between the ages of 7 and 19, Health Choice only covers one preventive health visit every three years. One pediatrician we interviewed said this makes it impossible to conduct annual sports physicals for adolescents and encourages fraudulent billing among providers.

A few other Health Choice benefits were considered inadequate early in implementation, and have since been rectified.

- **School-Based Health Centers.** When the original SCHIP legislation was crafted the House of Representatives specifically prohibited school-based health centers (SBHCs) from being Health Choice providers. As concerns regarding parental consent and coordination of medical care were addressed, and elections changed the configuration of the House, a SCHIP Plan Amendment was submitted and approved to include SBHCs as providers.
- **Dental Benefits.** The original Health Choice dental health benefit excluded sealants and extractions, an oversight that was attributed to the haste with which this portion of the bill was drafted. The law was subsequently rewritten with the aid of dentists to include these crucial benefits and passed by the General Assembly. The new dental health benefit became effective 1 July 1999.

To determine which services should be included in the Medicaid-equivalent wraparound benefit for CSHCN and, therefore, be paid out of the special funds for CSHCN, DPH officials compared the benefits available through Medicaid and the SEHP—the Health Choice benchmark package. To the surprise of many, the Health Choice core benefit was found to be deficient in few areas. The following services are included in the wrap-around benefit; with pre-approval, and if determined to be medically necessary, they will be reimbursed through the CSHCN special fund.

- **Physical Health.** The special fund will pay for service beyond the basic benefits, including programmable hearing aids and FM amplification systems; some nutrition therapies and special formulas; speech therapies for children with behavioral disorders; augmentative communication devices; assistive technologies; adaptive equipment and related DME, such as chairs, scooters, walkers, and ramps; and skin care and other supplies.
- **Behavioral Health.** The behavioral health wraparound benefit was described as a “dream come true” because Health Choice encourages the use of community-based resources. Services include day treatment; high risk intervention (HRI), a professional level of services that can include individual or group therapy, residential care, and group homes; and client behavioral intervention (CBI), a paraprofessional level of service that can be provided on an individual or group basis and may consist of such services as the Big Brother program. Children with developmental disabilities are eligible to receive outpatient treatment and high risk intervention.

For children who require both physical and mental health wraparound benefits, mixed-service protocols have been created. Eating disorders, panic attacks, autism, and pain management clinics are areas where these protocols are most often utilized.

In addition to these services covered through the Medicaid-equivalent wraparound, two key benefits are available to CSHCN enrolled in Health Choice that are *not* available through Medicaid—emergency respite care and service coordination. (In addition, the Health Choice package includes cochlear implants, a benefit not traditionally covered by Medicaid; after the SCHIP plan was implemented, DMA responded by adding this service to its benefit package.) To date, only the respite care benefit has been fully defined. However, the eligibility criteria and service coordination protocols for mental health, substance abuse, and developmental disabilities have been developed and implemented by ValueOptions.

- **Emergency Respite Care.** Officials defined this benefit as one that “can be provided to families for unplanned situations in which family members do not have the capacity to safely care for their child or when changes in their child’s health, behavior, or development require in-home or out-of-home temporary support.” Respite care services must be pre-approved by a ValueOptions mental health case manager and be provided by a BC/BS provider. DPH officials are now ready to enroll respite care providers and educate clients about how to access the benefit.
- **Service Coordination for Children Who Need Mental Health and Substance Abuse Services or Services for Developmental Disabilities.** Children must

meet the defined eligibility criteria as determined by ValueOptions mental health case managers. Reportedly, some providers fail to understand the difference between case support and case management. The former is not considered to be medically necessary and is not covered by Health Choice or Medicaid. ValueOptions has conducted provider training to remedy the situation.

- **Service Coordination for Chronic Physical Conditions.** Though case management is included in the Health Choice legislation, DPH has not yet fleshed out the particulars of the benefit. Among other activities, policymakers must develop identification, referral, and enrollment procedures; develop protocols for conducting assessments and developing service coordination plans; and develop an administrative infrastructure to handle provider qualifications, billing, documentation, reporting, and dispute resolutions. According to DPH officials, this is a high-priority task.

All of the services provided through the special fund for CSHCN must be pre-approved by BC/BS or ValueOptions. In reality, however, the special needs fund can be accessed both prospectively through the pre-approval process and retrospectively if providers fail to obtain pre-approval.

- Pre-approval requests for physical health services are submitted to BC/BS for initial processing. Questions related to services that are not covered under the core benefit are referred to two nurse case managers appointed to administer the special needs benefit. All authorizations for services are then forwarded to the appropriate member of the clinical team housed in the C&Y Branch of the Division of Public Health.¹⁵ The appropriate clinical team member reviews the request, makes a decision, and notifies the BC/BS case manager of the decision within two weeks. BC/BS then contacts the provider to inform them of the decision. BC/BS processes about 5 to 10 prior approvals for CSHCN each week and estimates that 90 percent of services for CSHCN are paid through the prior-approval process, as most providers are familiar with this requirement.
- Pre-approval requests for mental health, substance abuse, and developmental disability services are fielded by staff of the ValueOptions customer service phone line. Two clinical case managers who are experts in children's services conduct assessments over the phone and forward treatment requests to the ValueOptions Special Services Committee or the Medical Director, who decide whether or not the requests meet the pre-defined criteria for medical necessity. The case managers then inform the providers of the decision to certify or deny the requested services. From 1 October 1998 to 30 August 1999, ValueOptions fielded over 7,500 calls requesting certification of treatment; many of these

¹⁵ The DPH clinical team includes a physician and three other consultants who specialize in nutrition, physical therapy, and speech and hearing.

requests were covered under the core benefit.

- Retroactive approval for the special fund for CSHCN can also be granted. The BC/BS audit process identifies roughly 15 claims each day for services that are typically provided to CSHCN but have not been granted prior approval. These claims are then forwarded to the two BC/BS nurse case managers, who in turn may route them to DPH or ValueOptions for further review. The same procedures outlined above are then followed.

If a service is approved, BC/BS flags it for payment either through the core benefit or through the special fund for CSHCN. If a claim is denied altogether, both the family and provider are notified. Very few claims have been denied to date. The Commission reviews all the denied claims at their bimonthly meetings and have found them all to be appropriate.

It was reported that the BC/BS case managers have approved nearly all requests as covered under the basic benefit package; thus, only \$100,000 of the \$15 million fund had been spent at the time of the site visit. This may be seen as reflecting both the breadth of this package and the liberality of the case managers (particularly within a financial structure that provides no incentive to deny services). However, others fear this may indicate an underutilization of services among CSHCN enrolled in Health Choice or that CSHCN have not been able to gain access to the program.

C. Service Delivery

Children enrolled in Health Choice are served through a statewide indemnity system for both physical and mental health services. Any licensed provider in the state can be a Health Choice provider (with the exception of marriage and family therapists, who have not been approved by the legislature to provide mental health services under the program). Though the state statute allowed for MCOs to serve as Health Choice providers, no agency has responded to this provision, claiming the population eligible for Health Choice to be too small. In general, managed care penetration is minimal in North Carolina, and only one of the state's 100 counties is served through a fully-capitated mandatory Medicaid managed care system.

The General Assembly was adamant that Health Choice should not have a formal provider

“network;” hence the creation of the wide-open indemnity program. The number of primary care physicians and specialists who accept Health Choice is thought to be larger than those who accept Medicaid. This is especially true of dentists in North Carolina, who have traditionally avoided Medicaid, and of specialists and urban providers who have more flexibility in determining the composition of their caseloads. It is believed, however, that in most rural areas, the Medicaid “network” is equivalent to the Health Choice “network” as providers cannot afford to exclude low-income patients from their practices. Officials noted that families who have some children enrolled in Medicaid and some in Health Choice, may have to take their children to different providers.

The network of mental health professionals is also thought to be broader under Health Choice as the program covers services provided by a range of private providers. Medicaid, on the other hand, only reimburses psychiatrists, Ph.D.-level psychologists, and area mental health programs. As a result, families who are served through Health Choice and then become eligible for Medicaid, or vice-versa, may have to change mental health providers. It was noted that some children cannot find inpatient mental health care in some rural areas of the state. ValueOptions works with these family to amend the treatment plan or to locate a provider in another county.

While allowing for carte blanche access to service providers—a feature that families reportedly like—the lack of a formal network has hampered the ability of DPH staff to refer families to providers in their area known to accept Health Choice. The DPH Special Needs Helpline staff can, however, give families the names of providers who have submitted Health Choice claims. According to public health officials, the restriction against circulating lists of Health Choice physicians is especially problematic for CSHCN who may need to see a specific type of pediatric subspecialist in their community.

Another drawback of North Carolina’s indemnity model is the fact that children are not assured a medical home, as they would in a primary care case management model or a fully-capitated system, making it difficult to track and monitor services for a particular child. Again, we heard from advocates that this is more of a problem for CSHCN than it is for children without chronic conditions. For example, the rich mental health core benefit allows for 26 unmanaged

outpatient behavioral health visits each year. This presents a challenge for mental health professionals who may serve these children in other service settings after they have been certified for additional mental health wraparound benefits. According to one mental health provider, they may know very little, if anything, about the services previously received by the child under the core benefit.

After a child has exhausted his or her mental health benefits under the core plan, they begin using wraparound services, which are provided in an environment that more closely resembles a managed care system. ValueOptions works with providers to determine the most appropriate treatment plan for each child. Mental health officials said that some providers are accustomed to Medicaid's more lenient approval process and are now being forced (sometimes resentfully) to think more carefully about their prescribed treatment plan. ValueOptions staff report that even if they cannot certify all the coverage requested by a provider, they are able to certify an alternative plan with the wide range of services that is available through Health Choice's continuum of mental health services.

D. Payment

The state allocates Health Choice funds to the SEHP based on a per-child-per-month premium. These premiums were originally set at \$85-87 per child per month for children with family incomes below 150% of poverty and \$100-107 per child per month for those with incomes between 150-200 percent of the FPL. The SEHP premium payments were later adjusted based on the first six months of paid Health Choice claims. The revised premiums of approximately \$96 and \$122 per child per month, respectively, became effective 1 July 1999.

Neither BC/BS or ValueOptions incur financial risk, but serve strictly in an administrative capacity for the SEHP. The SEHP pays BC/BS an administrative fee equivalent to three percent of paid Health Choice claims. BC/BS pays ValueOptions a 59 cent per member per month processing fee for certifying mental health and substance abuse services. DPH also pays ValueOptions 8 cents per member per month for certifying developmental disabilities and respite care services and for administering the behavioral health wrap around services for

CSHCN.

All Health Choice providers are reimbursed on a fee for service basis through BC/BS. Health Choice pays providers 80 percent of usual and customary fees for all health services covered under the Health Choice core benefit. For almost all CPT codes, Health Choice rates are higher than Medicaid's; the exception being for well-baby and preventive health visits, which are reimbursed at a higher rate by Medicaid. Health Choice does not adjust its rates for CSHCN; providers who serve these children are paid the same fees for the same services as providers who serve children without chronic conditions. Services that are provided and approved to be paid out of the special fund for CSHCN are paid using the Medicaid fee schedule.

North Carolina has adopted two cost-sharing provisions—an annual enrollment fee and co-payments. Families with incomes above 150 percent of the FPL are responsible for paying an annual enrollment fee of \$50 per child up to a maximum of \$100 per family. The fee is due to the county DSS office within ten days of enrollment. Families with incomes above 150 percent of the FPL are also responsible for co-payments: \$6 for prescriptions, \$5 for physician visits, \$5 for outpatient hospital visits, and \$20 for “unnecessary emergency room use.” The co-pay requirement does not apply to preventive care.

Some evidence suggests that the annual fee may be a deterrent to enrollment. Failure to pay the enrollment fee is the number one reason for Health Choice denials, and accounts for 27 percent of all denials. Also, only 30 percent of those enrolled in Health Choice have family incomes above 150 percent of the FPL—considerably less than the CPS estimate of 50 percent. Though the enrollment fee is thought to have a negative effect on many families applying for Health Choice, many do not believe the fee serves as a deterrent for families of CSHCN, as they are accustomed to paying considerable out-of-pocket costs for private insurance.

E. Quality Assurance

The North Carolina General Assembly has stipulated a number of Health Choice annual reports that must be submitted to the Joint Legislative Oversight Committee and the Joint

Appropriations Subcommittees on Health and Human Services. The DMA must also submit a number of reports to the Health Care Financing Administration each year. Among other quality measures, North Carolina has agreed to develop a “HEDIS-like measurement” for its indemnity delivery system. Specific measurements related to CSHCN will also be submitted to HCFA annually.

In addition to preparing required reports, the DMA is working with other agencies on a number of Health Choice quality monitoring initiatives:

- The DMA designed a customer satisfaction survey;
- In collaboration with the Cecil B. Sheps Center at the University of North Carolina School of Public Health, the DMA conducted a random sample mail survey of Health Choice enrollees to determine their previous insurance status and how children are accessing services;
- The Jordan Institute at the University of North Carolina’s School of Social Work is examining the impact of continuous eligibility on enrollment; and
- The Robert Wood Johnson Foundation and others are examining the county-based outreach initiatives.

Though the DMA is ultimately responsible for quality assurance, DPH, BC/BS, ValueOptions, and the Commission all play a role in quality assurance for CSHCN.

- DPH is currently designing a quality assurance mail survey for CSHCN enrolled in Health Choice identified through BC/BS claims data. The survey has been field tested and is projected to be mailed by summer of 2000. Eventually, they hope to administer the same survey to CSHCN enrolled in Health Check.
- ValueOptions tracks all the calls they receive for certifications, developed an appeals process for mental health and developmental disabilities services that are denied, plays an active role in the Behavioral Health Work Team, sponsors provider trainings, and is planning to conduct a satisfaction survey in conjunction with the SEHP.
- BC/BS provides a number of reports to the C&Y Branch of the Division of Public Health:

BC/BS produces quarterly utilization reports sorted by diagnosis code. These reports include the total number of requests for special therapies, home nursing care, assistive technology and DME, hearing aids, mental health, developmental disabilities, respite care, and service coordination;

the number and percent of requests certified under the core Health Choice benefit and the special fund for CSHCN; and the number and percent of requests that are denied for both the core benefit and wraparound benefit, as well as the reason for denial.

BC/BS also submits reports arrayed by CSHCN diagnosis code that list services in descending order by expense and prevalence.

The proportion of children enrolled in Health Choice who are seen by a “board-certified specialist with pediatric experience” is also reported periodically.

BC/BS produces a report that profiles the children who receive service coordination and those who do not. This report is sorted by diagnosis code.

- The Commission on Children with Special Needs reviews copies of all denied Health Choice claims for CSHCN.

III. Lessons Learned

The collaboration among the SEHP, the DMA, the Division of Public Health, ValueOptions, and BC/BS in designing and implementing Health Choice was described by all parties as tremendously successful. The three key agencies meet weekly to resolve problems as they arise, the administrative agencies participate actively in Commission and Behavioral Work Group meetings, and each agency publicly recognizes the strengths of the others, leaving no evidence of turf battles. Moreover, North Carolina has gone to great lengths to involve families of CSHCN in every stage of program development.

One major benefit of the state’s SCHIP approach has been its effect on the Medicaid program. First, Health Choice served as the impetus for simplifying the Medicaid application process. Second, Health Choice outreach efforts are thought to have brought additional families into the system who are Medicaid eligible. And, third, an unanticipated bonus of basing Health Choice on the SEHP benefit package has been the ensuing enrichments in both the Medicaid and the SEHP benefit packages. In at least two instances, Health Choice’s superior benefits have led to the expansion of benefit under Medicaid or the SEHP:

- Because Health Choice covered cochlear implants, Medicaid officials added the

surgery to its benefits.

- The coverage of additional speech therapy services for children with behavioral disorders through Health Choice led Medicaid and SEHP officials to add them to their plans as well.

Public health officials were optimistic that this “domino effect” would continue as other incongruities in benefits were brought to their attention.

Another set of benefits has resulted from the combined effect of a separate state program, wraparound benefits, and a pure indemnity system. The selection of a separate state program administered by BC/BS makes the program more attractive to families and providers. While families enjoy participating in a program that looks more like private coverage than Medicaid, providers like dealing with BC/BS when it comes to billing and reimbursement. We heard from many different agency representatives that access is not a problem for CSHCN as the pool of Health Choice providers includes most primary care providers and specialists in the state.

Despite these benefits, observers are perplexed by the relatively light use of the wrap-around fund for CSHCN, despite the program’s high enrollment numbers. After only one year, 51,000 children were covered through Health Choice—nearly three-quarters of those projected to be eligible for the program. The advocates for the wraparound benefits for CSHCN did not estimate the number of CSHCN among the total eligible population. Instead, they expected the proportion of CSHCN enrolled in Health Choice to reflect national numbers, which range from 6 percent to 30 percent, depending on the definition of CSHCN. Using claims data, it has been determined that Health Choice has provided services to 4,057 children, or approximately 8 percent of those enrolled. The services provided to CSHCN represent roughly \$3.5 million, or 12 percent of total program expenditures, and less than \$100,000 has been utilized from the \$15 million in special funds for CSHCN.

One explanation for the discrepancy between the enrollment numbers and the use of CSHCN funds is that the state’s outreach program has exceeded expectations. Many lauded the foresight of the state to build upon the existing infrastructure of county coalitions and to embrace a “neighbor to neighbor” approach to promoting Health Choice. Another explanation

for the higher-than-expected enrollment was the extensive simplification of the Health Choice eligibility and enrollment process, including the shortened application, the mail-in option, and the single point of entry for Health Check and Health Choice. Finally, some believe the decision to institute a one-time enrollment fee over a monthly premium has prevented attrition and churning seen in other states' SCHIP programs.

Despite the generally high levels of enrollment, some believe that CSHCN are not accessing the program at the same rate as children without chronic conditions. Others, however, believe that the state is serving roughly the same proportion of CSHCN reflected in national estimates. The Chair of the Commission believes that Health Choice has captured most CSHCN who are eligible for the program as physicians have a fiscal incentive to secure coverage for their patients with special needs. The following hypotheses were presented when asked why so little of the \$15 million CSHCN special fund had been utilized:

- The enriched SEHP benefit package is meeting the needs of CSHCN. This was the most popular theory offered by case study participants to explain the underutilized fund for CSHCN. In practice, few services have been excluded from the SEHP coverage and shifted to the wraparound physical, developmental, and mental health benefit package. Also, the fact that BC/BS and ValueOptions are not at financial risk means there is no incentive for them to shift costs from the core benefit to the special needs fund, or to implement utilization management controls.
- Services for CSHCN are not as costly as expected. Others added that the figure of \$15 million was not estimated empirically, but was a political compromise in a special legislative session meant to ensure adequate funds for a vulnerable population. Therefore, the low expenditures do not necessarily reflect low utilization.
- Children with the most severe—and therefore costly—conditions are not enrolled in Health Choice. Some interviewees posited that children with the most severe conditions are already covered by either Medicaid or private insurance. In support of this theory are the following suppositions:

The high-cost population of infants under one year of age are covered by Medicaid in North Carolina.

After one year of age, children with the most severe conditions are covered by either SSI, Medicaid's medically needy program, or Medicaid waiver programs.

Children who “graduate” from Medicaid as they age have little pent-up

demand for services as they enter Health Choice as their needs have been met in prior years.

Families who have managed to acquire private coverage for their CSHCN do whatever it takes to maintain it. Staff of the Special Needs Help Line and members of the DPH Parent Advisory Group said many families have made employment decisions based on the availability of health insurance for their children, even if they must pay high premiums and out-of-pocket costs.

Families who otherwise qualify for Health Choice except for the fact that they have some form of private coverage cannot afford to take the risk of dropping this coverage for two months, as required by the Health Choice waiting period. Administrators of the Health Choice plan expected a significant increase in enrollment after the initial six-month waiting period had passed; however, it did not produce so much as a “blip” in enrollment. Advocates have deduced that parents of severely-ill children are not among those who can voluntarily drop coverage for even two months and opt for Health Choice. Advocates find the waiting period to be the greatest barrier for CSHCN seeking entry into Health Choice.

- CSHCN enrolled in Health Choice are not utilizing all the benefits available to them. Some believe that many of these children’s previous coverage was catastrophic in nature, or only covered certain components of their care, such as inpatient services. Now that they are enrolled in Health Choice, they continue to exhibit the same health care utilization patterns, and are therefore underutilizing services. It was suggested that with education and time in the program, these families will learn to more appropriately utilize available benefits.
- The service coordination benefit has not been fully implemented, nor has emergency respite care, two important services that will be paid for out of the wraparound fund.

Regardless of which theory is correct, the Commission is currently considering several options for making it easier for CSHCN to enroll in the program:

- Eliminate the waiting period for CSHCN or for all children.
- Increase the eligibility guideline to 300 percent of the FPL for CSHCN, or for all children.
- Allow CSHCN or all children with incomes greater than 300 percent of the FPL to buy-in to Health Choice.
- Allow children to enroll in Health Choice if they incur health care costs equivalent to 5 percent or more of their families’ yearly income.

A representative from North Carolina's Family Voices also suggested that Health Choice be allowed to serve as a secondary payer to children's primary source of coverage, if inadequate, as is permitted of the Medicaid program.

Despite the many advantages of North Carolina's approach, several disadvantages of the system were evident:

- **No Mechanism to Identify CSHCN.** In an effort to shorten and simplify the joint Health Check/Health Choice application—a victory with many positive effects—advocates had to compromise on the omission of a screening question on the application to identify CSHCN at enrollment. Described earlier in the report, DPH has had to go to great lengths to retroactively identify CSHCN. These mechanisms have been criticized by some as insufficient, as they track diagnoses and services, rather than children. Some advocates believe that the failure of the program to identify these children makes it easy to overlook their needs and difficult to make timely improvements in the program.
- **No Formal Network.** Once in the system, families may lack information about available providers, since the state legislation prohibits the creation of an exclusive network. Again, Commission members, public health officials, and advocates are concerned that they do not possess effective tools to consistently refer families of CSHCN to specific providers in their area. As one interviewee pointed out, it is difficult to find a pediatric dentist who will serve CSHCN. It's a disservice to families to not share the names of the few Health Choice dentists who would be willing to serve their children.
- **No Medical Home.** Once children have found a provider, there is no mechanism to ensure that the provider orchestrates their care. Had Health Choice been a Medicaid expansion, all children would have had a medical home through the state's Medicaid primary care case management program. This is a particular concern for CSHCN, who are often under the care of several physicians of varying specialties. In addition to the risk that the quality of children's medical care may be compromised, it is more difficult for DMA to collect data on CSHCN as providers are not accountable to any particular health plan and to hold providers responsible for quality assurance purposes. ValueOptions has also said that the lack of a medical home complicates their efforts to conduct targeted provider education on particular policies.
- **Delay in Implementing the Case Management Benefit for Children with Physical Health Conditions.** One of the strongest features of the wraparound benefit package for CSHCN enrolled in Health Choice has not yet been operationalized. Declared as their next priority, the importance of this benefit is not lost on DPH officials who have been consumed by getting the CSHCN framework, the Commission the quality assurance survey, and the respite care

benefit in place. However, at this time, this gap can be perceived as the Achilles' heel of the Health Choice program. Once it is put in place, however, it will do much to compensate for the fact that in the North Carolina indemnity system, children do not have a medical home.

In summary, it appears that CSHCN enrolled in Health Choice enjoy a comprehensive SCHIP benefit package and have a wide array of health care providers to choose from. However, the nagging question at this time is how many families of the most seriously ill CSHCN cannot gain access to the program due to the waiting period restriction or the difficulty of identifying eligible children. Unfortunately, the answer to this question is not an easy one to uncover, but is essential for evaluating the relative success of the program in meeting the needs of CSHCN in North Carolina.

Case Study: Pennsylvania

I. Background and Overview

Child health insurance coverage was a high-priority issue for former Pennsylvania Governor Casey's administration. The administration's advocacy for universal health care spawned the introduction of various health insurance bills, ultimately leading to passage of the Children's Health Insurance Act in 1992. This Act provided free health insurance coverage to approximately 29,000 uninsured children ages 1-6 in families with incomes under 100 percent of the FPL and subsidized coverage for children under age 6 up to 235 percent of the FPL under a program called PaSCHIP.

Modeled after the Blue Cross Blue Shield Caring Program, the intention of the original PaSCHIP program was to provide health care coverage for uninsured children in working families.¹⁶ The program was modestly funded through a \$.02/pack cigarette tax and \$10 million in appropriated general state funds and it aimed to provide a basic package of health care services for children. The program's benefits included primary and preventive health care services, 90 days of inpatient care, prescription drugs (with a \$5 copay), and hearing, dental and vision screenings and eyeglasses. Soon after implementation, PaSCHIP coverage was expanded to children ages 1-13 up to 185 percent FPL and mental health benefits were added as well. The Blue Cross Caring Foundations then acted as a wrap-around program, covering children ages 14-19 up to 185 percent of FPL.

When the Balanced Budget Act was passed in 1997, Pennsylvania was one of three states with an existing child health insurance program grandfathered into the Title XXI program.

Therefore, Pennsylvania used SCHIP funds to expand coverage under the existing PaSCHIP

¹⁶ The Caring Program was established in Western Pennsylvania in the late 1980's following steel industry layoffs to provide transitional coverage for uninsured children in families with income between 100-150 percent FPL.

program to serve uninsured children through age 16 with family income at or below 200 percent of poverty, with subsidized coverage available to children with family incomes between 200 and 235 percent of poverty. (Families in the subsidized program are responsible for one-half the monthly premium.) This expansion was approved in May 1998.

PaSCHIP's benefits include inpatient and outpatient services, prescription drugs, and dental, radiologic and laboratory services, plus additional in- and out-patient mental health services. The PaSCHIP Title XXI program was designed as a separate state program primarily to capitalize on the existing infrastructure and provider network. Children with special health care needs (CSHCN) are enrolled in the same program as typical children for both primary care and specialty care; therefore, PaSCHIP is considered a mainstream model for CSHCN.

The original PaSCHIP program was administered by a tri-agency management team composed of the Governor's Budget Office, the Department of Health and the Insurance Commission. Following the expansion of the program, the Insurance Commission was assigned sole administrative responsibility. Other state departments remain involved in PaSCHIP: the Department of Public Welfare continues to play a role in eligibility and the Health Department is involved in outreach activities. Additionally, the Children's Advisory Council, established when PaSCHIP began and chaired by the Secretary of Health, was expanded to include the Secretary of Public Welfare, the Insurance Commissioner, members of the Pennsylvania General Assembly, representatives from health care provider groups and a parent of an enrolled child. The council oversees outreach activities.

A three-day site visit was conducted in Pennsylvania in October 1999 to further examine the PaSCHIP program and its services for children with special health care needs. During the site visit, interviews were conducted with representatives of the Insurance Commission, the Health Department, the Governor's Policy Office, managed care organizations, a child advocacy organization and state legislative staff. Telephone interviews were conducted with PaSCHIP providers.

This report presents a detailed description of our findings. The following section describes

issues related to the PaSCHIP program’s eligibility, outreach, enrollment provisions; benefits and service delivery systems; financing; and quality monitoring. The final section of the report provides an analysis of our findings and lessons learned from the first year of the Title XXI program.

II. The Pennsylvania Model

A. Eligibility, Enrollment, and Outreach

To be eligible for PaSCHIP, a child must be uninsured and ineligible for Medicaid.¹⁷ A second amendment of Title XXI PaSCHIP, effective September 1999, included a new eligibility formula, known as the “net income test,” to determine the amount of family income counted toward eligibility for coverage. Work expenses of up to \$90 per month for each employed person in the household and incurred child care expenses up to \$200 per month per child are now deducted from a family’s gross earnings to calculate their net income, effectively raising the program’s upper income limit by reducing countable income. It was estimated that an additional 124,000 Pennsylvania children may be eligible for PaSCHIP under the new guideline.

There is no waiting period or other provision in place specifically to deter crowd-out. Families are required, however, to report all existing health insurance coverage for their children at the time of application; they must be uninsured and ineligible for Medicaid to be eligible for SCHIP. All families applying for PaSCHIP are screened for Medicaid income eligibility and applicants are referred to Medicaid if they meet the income guidelines. SCHIP plans have the capacity to compare eligible families to their own subscribers to verify whether the family has private or employer-based coverage. In addition, a cross-match system with Medicaid has been set up to determine whether SCHIP applicants are already enrolled in Medicaid. The cross-match, run monthly on all new SCHIP applicants, has averaged only a 3 percent “hit rate” in the past year.

¹⁷ Current Pennsylvania Medicaid eligibility levels are as follows: Children ages 0-1 with family incomes up to 185% FPL; Children ages 1-5 with family income to 133% FPL; Children 6-12 years old below 100% FPL; and Children ages 13-18 with family incomes at or below 44 percent FPL.

As of September 1999, 82,963 children were enrolled in PaSCHIP—nearly 67% of the 124,000 uninsured children estimated to be eligible for SCHIP. Outreach, eligibility determination, and enrollment are administered separately by the plans, although their contracts contain some specific requirements (such as a toll-free number to provide enrollment information to applicants.) Each plan produces its own application form, but specific questions must be included on all application forms. A standard one-page application form is under development, and the state is also developing a combined application for Medicaid and SCHIP.

At the start of the PaSCHIP program, if a family appeared to be Medicaid-eligible, they were referred to a county assistance office to fill out a Medicaid application. Currently, pending finalization of a common application, SCHIP has established an “any form is a good form” agreement with Medicaid, allowing information submitted on the SCHIP application form to be accepted for a Medicaid application and vice-versa. Now the SCHIP application may be forwarded to Medicaid to begin the eligibility process without requiring the family to go to the county assistance office to complete a separate application. Conversely, a family’s Medicaid application may also be forwarded to a SCHIP contractor (where there is more than one plan, applications are sent to plans on a rotating basis). This is reported to be particularly helpful to families whose children are eligible for different programs.

As mentioned above, children with special health care needs are enrolled in the mainstream PaSCHIP system; however, the program was designed with the assumption that most low-income children with serious medical needs would be eligible for Medicaid. Historically, Pennsylvania’s Medicaid program has used the individual income rule available under OBRA ‘89, which allows the income of disabled and elderly individuals to be evaluated independent of their household or family. This rule has allowed most children with significant special health care needs to qualify for Medicaid in Pennsylvania.

To indicate potential eligibility for SSI and Medicaid, all PaSCHIP applications are required to include a question regarding special needs. The applicant is asked to indicate whether their child has “a chronic illness or disability.” A disclaimer precedes the question assuring the family that disclosure of a pre-existing illness or disability will not affect the child’s eligibility and that

the information is confidential. The open-ended CSHCN question generates a wide variety of responses, ranging from disclosure of mild allergies and the need for eyeglasses to severe life-threatening conditions. Because of the question's breadth, very few of the responses have proven useful in identifying potential Medicaid/SSI eligibility.

Data from the special needs question are generally used by physicians, when used at all. The physicians interviewed indicated that the answers to the special needs question are used informally to identify children who may need disease management and/or referrals to specialists; however, more specific identifying information on the application would be needed to utilize the data systematically. The problems associated with utilizing the data from the special needs question were reiterated by representatives of the managed care plans, who indicated that, since there is currently a lack of agreement on the definition of "special needs" in the state, it is difficult to know what information will be most useful to track. State officials are therefore considering asking a more detailed series of questions to identify CSHCN more specifically in order to monitor their care.

Neither the plans nor the state uses the data to identify children with special needs enrolled in the program and the state has not developed alternative mechanisms to identify CSHCN. Identification of these children has not been a priority, since the program offers no special services or program provisions for this population. Instead, greater focus has been placed on identifying all children eligible for SCHIP. In addition, the Title V CSHCN program is available to SCHIP enrollees and will provide coverage for specific services that have been requested by a physician but denied by the SCHIP program.^{18, 19}

Outreach is mandated in the state SCHIP legislation and is administered at both the state and plan levels. The Health Department has been involved in statewide outreach efforts including a

¹⁸ Title V is housed in two divisions within the Bureau of Family Health: The Division of Special Health Care and the Maternal & Infant Division. State administered Title V programs operate in 60 of 67 counties in the state supporting a network of community health nurses, injury prevention services and outreach to children and pregnant women.

¹⁹ The Health Department indicates that only one family has utilized this option to date. Coverage was provided for special formula for an infant with PKU.

multi-media campaign and the establishment of a toll-free number to provide the public with information about the program. In addition, each of the five participating insurance companies is mandated by contract to conduct a range of outreach activities. In the past year, these activities have included presentations, one-on-one talks and educational materials to local businesses, school districts, hospitals, religious organizations, civic groups, day care centers, social service agencies and civic groups. Although general activities and information distributed may be similar among the plans, the overall outreach plan and staffing patterns vary among contractors. Examples of the plans' outreach efforts include:

- Highmark Blue Cross/Western Caring Foundation hired an outreach manager to oversee three outreach staff members. They have produced literature promoting their 800 number for families to obtain more information and distributed written materials to local faith organizations and social service agencies. Highmark is also working closely with schools to promote SCHIP enrollment. Mailings are distributed to school superintendents and school nurses each year requesting that the SCHIP literature be sent home with children on the first day of school and that school nurses track whether the insurance coverage section of each child's medical card is completed. If the section is not completed, the school nurse follows up with families to inquire about the status of health insurance coverage for the child.

- Capitol Blue Cross/ Caring Foundation of Central Pennsylvania operates its outreach program primarily by responding to requests for information and participation in activities made by their outreach partners. An outreach coordinator is responsible for responding to requests from organizations for presentations, fair displays, and materials, but she does not plan or sponsor outreach activities. Capitol Blue Cross boasts a network of 1200 community-based outreach partners in their service area with whom they work to promote SCHIP outreach.

Outreach activities are also conducted in four communities throughout the state by the Pennsylvania Partnership for Children, the Covering Kids grantee. Two outreach models are being piloted by the project: 1) a coalition model in which churches, schools and other key organizations in the community are encouraged and supported in the development of a coalition to promote SCHIP outreach; and 2) an agency-based model in which a \$25 fee is paid to agencies for each complete SCHIP application form they submit. The Covering Kids project has tried to increase the state's awareness of the special needs population in their outreach

activities by encouraging the addition of TTDY capability for the information hotlines and alternative forms of brochures to ensure that parents with special needs have access to information about the program.

B. Benefits

The approved Pennsylvania Title XXI benefit package was the original, relatively inclusive PaSCHIP benefit package. It offered up to 90 days of inpatient care; physician and surgical services (with the exception of cosmetic surgery); clinic services; prescription drugs, laboratory and radiological services; inpatient mental health services up to 90 days (these days can be converted to outpatient visits at a 2:1 ratio); and up to 50 outpatient visits per year. Additionally, the package included case management; hospice care; and ambulance services when medically necessary. One service specifically excluded from PaSCHIP is prenatal care. This was reported to be a serious gap in coverage of adolescents.

In September 1999, the benefit package was amended to include additional specialty services. These additions were an attempt to increase the overall comprehensiveness of the package, for both CSHCN and typical children, given the availability of Federal Title XXI funds. The additional benefits were a result of child health advocates' long-fought battle to increase coverage of mental health services, rehabilitative therapies and home health services for all children. The additional benefits included:

- Durable medical equipment;
- Other medically related or remedial devices such as hearing aids, prosthetic devices, implants, and eyeglasses;
- Special formulas for children with metabolic disorders;
- Home- and community-based health care, such as nursing services and post-operative care;
- Drug abuse treatment; and
- Rehabilitative therapies (physical, occupational, speech and respiratory therapy).

The amendment also eliminated the \$5 co-payment for prescription drugs that was included in the original PaSCHIP plan.

Beyond these important additions, no provisions or additional benefits have been provided specifically for children with special health care needs (CSHCN), and it appears that the program is meeting children's needs. Given the strong voice of child health advocates in Pennsylvania, state administrators, managed care representatives and providers interviewed agreed that advocates would have alerted them about any serious gaps in the program's benefits. The managed care representatives also indicated that they would have expected feedback through their customer service department if families of CSHCN were having difficulty getting the services they need. A western Pennsylvania plan administrator stated that "it's [serving children with special needs] just never been an issue." In the one and half years since the Title XXI implementation, he indicated that no more than ten denial letters have been issued regarding requests to cover special services. He was certain that the number of denials would have been higher if there was an issue regarding lack of coverage for needed services. On the other hand, others note that families may not be well-enough informed to ask for referrals for newly-covered services for their children.

C. Service Delivery Systems

Prior to implementation of Title XXI, the PaSCHIP program worked with insurance companies on a grant basis. The participating health insurance companies, which were at the time all Blue Cross/Blue Shield organizations, were given a sum of money and allowed to administer the program as they chose. In June 1999, the state began procuring contracts on a competitive (RFP) basis for the provision of SCHIP services. At the time of the site visit, PaSCHIP services were being provided statewide under a managed care model through contracts with five insurance companies, one of which is a state-licensed HMO and the rest of which are not-for-profit subsidiary foundations of large health insurance companies, all Blue Cross/Blue Shield affiliates. The contractors are: Aetna U.S. Health Care, Western Pennsylvania Caring Foundation/Highmark Blue Cross, Caring Foundation of Central Pennsylvania/Capitol Blue Cross, Caring Foundation of Northeastern Pennsylvania and the Independence Blue Cross Caring Foundation.²⁰ The non-profit foundations carry a range of managed care and fee-for-

²⁰ Western PA Caring Foundation, Independence Blue Cross Caring Foundation, and Aetna U.S. Healthcare also offer privately funded health insurance coverage for low-income families not otherwise

service products. A sixth health insurance company, Three Rivers Health Plan, has been approved to operate in ten counties in the southwest area of the state, and a seventh, Health Management Alternatives, will operate in the five-county Philadelphia region.

Ninety-nine percent of enrollees are served by managed care programs; those who are not are served through Preferred Provider Organizations (PPO) or fee-for-service arrangements. Five counties in western Pennsylvania lack managed care plans because of insufficient provider networks in those areas. No services are carved out of the responsibility of the managed care plans, but contractors may sub-contract with other plans for services. All plans must allow pediatric specialists to be designated as a child's primary provider as requested. Although the language of the contracts is somewhat general, they indicate that all contractors are responsible for the full range of program administration, including eligibility determination, outreach, and premium collection, as well as managing health services and paying claims.

Pennsylvania may be unique in the breadth of its contractors' networks because of the domination of the Blue Cross organizations and Pennsylvania Blue Shield, which tend to include most of the providers in their service areas, in the state health insurance market. Nonetheless, pediatric specialists are sometimes in short supply. Accessing providers for allergy-related skin testing and laryngology is particularly difficult. The physicians felt that the problem of specialists' availability is not specifically related to the SCHIP service delivery system, but is a product of the shortage of specialists available outside of the two primary Children's Hospitals in the state (located in Pittsburgh and Philadelphia). Many providers also reported difficulty finding dentists within the SCHIP system, but some state officials denied that this was an issue. In addition, physicians reported that it is often difficult to obtain authorization from the MCOs for prescription drugs.

In general, the wide availability of providers to serve CSHCN is likely to be related as well to the systems development efforts of the state's Title V CSHCN program. No longer a provider of direct services, this program is now devoted to the assurance of a comprehensive system of

eligible for SCHIP or Medicaid.

care for CSHCN. For example, Title V sponsors the Special Kids Network, a statewide system designed to facilitate linkages between families of CSHCN and community agencies, services, and providers. The Network helps parents access services and facilitates service coordination for CSHCN by providing information, referrals and support to families through a statewide toll-free number. In an effort to assure that a comprehensive system of care exists for CSHCN, the Title V programs attempt to inform parents of available resources and link them with a variety of services, including the following:

- **Education and Training** - Braille instruction, adaptive driver training, independent living skills, family resource libraries;
- **Health Care Products** - Adaptive clothing, standing and walking aids, wheelchair repair, assistive technology;
- **Parent-to-Parent of Pennsylvania** - Links parents who have experienced similar situations related to CSHCN;
- **Recreation and Leisure** - Recreation and therapeutic camps, Special Olympics, wheelchair sports, playgrounds with adaptive equipment;
- **Social Services and Counseling** - Adolescent, child or family counseling, bereavement counseling, hospice care;
- **Support and Advocacy** - Parent and sibling support, special education advocacy, legal rights advocacy; and
- **Therapy** - Physical, occupational, speech, play and equestrian therapy.

D. Payment

The state match for the Title XXI program is generated from a 3 percent tax on cigarettes (\$31 million in FY 1998) and state general funds appropriations (\$15 million in FY 1998). The plans are paid on a capitated basis and the rates vary based on their actuarial analysis and geographic service area. The rate is not risk-adjusted and no special payments are made for children with special health care needs. The method through which physicians are paid varies. Some providers are paid by capitation while others, such as the Harrisburg and Paoli Hospitals, bill fee-for-service as SCHIP enrollees are seen by their physicians.

The lack of risk adjustment for physicians paid on a capitated basis raised mixed opinions among the physicians interviewed. One physician indicated that children with special needs are seen more often for referrals and require more time in each office visit; therefore, the rate should be adjusted. Another physician acknowledged that additional time is needed in serving children with special health care needs, but felt that no additional funds were needed to serve CSHCN. In general, however, capitation rates for SCHIP were considered by physicians to be too low.

E. Quality Monitoring and Oversight

Quality assurance and quality management issues were a major focus of PaSCHIP at the time of the site visit. A new task force formed to examine quality issues was scheduled to meet in November 1999. Task force members include the SCHIP management team, Medicaid Director, Directors of each of the contracted insurance companies, and representatives from the state Pediatric Association. One issue that will be explored is ways in which the program can be compared with other states' SCHIP programs and EPSDT on standards of performance and quality.

A performance assessment of the SCHIP contractors was conducted at the start of the Title XXI expansion to be used as a baseline. The state plans to combine the results from the baseline assessment with the Healthy People 2000 goals to develop future performance measures. Periodically, additional quality assurance data will be available from the NCQA (National Committee for Quality Assurance) review, given that each state-licensed HMO is required to undergo the review every three years. Other quality assurance efforts required of the contractors include the following:

- Each contractor must conduct standard satisfaction surveys and develop a quality improvement plan that delineates ways in which they will improve their delivery of preventive and primary health services for SCHIP enrollees. The Department of Insurance works with the contractors to address service deficiencies and meet their goals.
- Contractors must provide a grievance resolution process for SCHIP enrollees.

Grievances not satisfactorily resolved through this process may be appealed with the state SCHIP administration.

- Although there is no electronic data processing systems yet, data on enrollees' service use patterns, grievance reports and billing are submitted to the state regularly. The state has hired a contractor to develop a system of data collection that will allow more systematic collection of information on the demographics of children served. As part of the new data system, contractors will be required to link electronically to a central data system and additional data will be collected on quality and appropriateness of care according to the guidelines of the Centers for Disease Control and Prevention, American Academy of Pediatrics and HEDIS.
- Currently, impact/outcome studies of the PaSCHIP program are conducted periodically through state contracts with Pennsylvania State University. The studies focus on assessing preventive and health maintenance services provided under PaSCHIP. Future studies may be expanded to include a wider variety of performance measures such as access and availability.

State officials feel that the assessment of services for children with special needs will ultimately become the responsibility of the plans. As part of an effort to develop mechanisms through which access and utilization can be tracked, the PaSCHIP management team is in the process of modifying the SCHIP application and they are considering changing the way in which information on special needs is collected. New questions requesting the child's specific special needs medical diagnoses (e.g. diabetes, asthma) may be included on the application to provide reference data for utilization tracking. The SCHIP Director indicated that since HMOs in the state are dually licensed by the Department of Health and the Department of Licensing and the SCHIP program is housed within the Insurance Commission, the PaSCHIP program is well suited to ensure that its contractors are providing adequate and quality care for the SCHIP enrollees.

III. Lessons Learned

Since Pennsylvania has utilized the individual income rule that allows the income of disabled and elderly individuals to be evaluated independent of their household or family, most children with significant special health care needs qualify for Medicaid in Pennsylvania. Therefore, the

Pennsylvania Title XXI program was not designed with specific provisions for children with special health care needs. Rather, a comprehensive benefit package was designed which was assumed to be adequate for all eligible children.

Unlike most other states, the PaSCHIP program has been in existence for several years and was well established in the public mind by the time the expansion under Title XXI was authorized. Therefore, the program's early efforts at outreach and enrollment activities have been unusually successful, enrolling two-thirds of the estimated number of eligible children. Since the program offers no specific services for children with special needs, however, no efforts have been made to reach out to and enroll this population. Program administrators are now beginning to shift attention to benefits and service delivery-related issues, such as how best to serve special populations; however, they are focused more on children at psychosocial risk, such as runaway teens and homeless children, than on children with complex medical needs.

While a strong child health advocacy community is active in the state, it is important to note that little discussion has been initiated regarding the need for additional services or other special provisions for children with special needs. Historically, at the inception of the original PaSCHIP program, fiscal limitations and enrollment caps necessitated limits on general outreach and particularly outreach to special populations. As federal Title XXI funds became available, there was a scramble to fill these new slots. Case study participants hypothesize that several assumptions were made about children with special needs which precluded efforts to target them in the expanded program as well:

- The most severely needy children are in Medicaid/SSI. The individual income rule utilized in the state effectively eliminates the upper income limit for most children with disabilities, thus allowing virtually all children with significant special health needs to qualify for Medicaid. It is assumed that Medicaid will cover all needed services for the population.
- Enrollees' special health needs are met under SCHIP. Respondents pointed out that the SCHIP benefit package is fairly comprehensive; therefore, it may be able to meet the needs of children with less severe special needs, since many services such as DME, home and community-based health care, rehabilitative therapies and prescriptions are provided without specified utilization limits.

- Enrollees seek special services outside of SCHIP. Families of CSHCN are likely to be familiar with resources available in the state and may take advantage of private and community-based services to fill in gaps in need. Physicians may refer or link families with such programs for services that are not covered by the families' insurance plan.

The general consensus among the case study participants is that SCHIP enrollees with special needs are likely to have mild to moderate special needs, but would not qualify for SSI and Medicaid; therefore, they may not need services beyond those provided through the comprehensive SCHIP benefit package. If families were not receiving the services they need, given the adequate grievance processes required of plans and the active advocacy community in place, case study participants were unanimous in their opinion that negative feedback would have been generated by now by both families and advocates.

Child health advocates pointed out that an alternative to the mainstream model was briefly raised at the inception of the original PaSCHIP program in the form of a carve-out for children with special needs. However, policymakers were concerned that the estimated number of children eligible for such a program was too low to justify its development. Ultimately it was decided that if the benefit package were comprehensive, PaSCHIP would be able to adequately meet the needs of SCHIP-eligible children.

The major problem that arises in the mainstream model is that, without adequate data collection mechanisms to track special populations, policymakers cannot know whether these children are able to access and utilize the services they need within the SCHIP program or what services they do utilize. With the development of a comprehensive electronic data collection system and increased focus on benefits and service delivery issues and outcomes for special populations, it seems that, in the coming year, PaSCHIP will be in a better position to assess how well the mainstream model is actually working for children with special health care needs and for the plans. There may, in fact, be an incentive for the insurance plans to initiate identification of special needs children and analyze their service use to track high-cost enrollees and perhaps, in the future, make a case for adjusted rates or alternative service delivery arrangements that meet the needs of children in the most effective and cost-efficient manner.