

New Opportunities, New Approaches:
Serving Children with Special Health Care Needs Under
SCHIP

Volume I: Synthesis of Study Results

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I. Introduction and Overview

The State Children's Health Insurance Program (SCHIP), created as part of the Balanced Budget Act of 1997, offers states an unprecedented opportunity to extend health coverage to uninsured children of low-income working parents. As has been widely discussed (Mann and Guyer, 1997; Rosenbaum, et al., 1998; Ullman, et al., 1999), SCHIP allows states to extend Medicaid coverage, create separate programs, or use a combination of the two to cover uninsured children with family incomes up to 200 percent of the Federal Poverty Level (FPL).¹

The goal of the SCHIP program is to provide coverage to uninsured children, a group that may include a significant population of children with special health care needs (CSHCN) whose families have not been able to afford coverage for them. It has been estimated that nearly 17 percent of low-income uninsured children meet a broad definition of CSHCN, meaning that they have chronic physical, developmental, behavioral, or emotional conditions and require services beyond those needed by typical children (Newacheck et al., 1998; McPherson, 1998). This population includes children whose chronic conditions create functional limitations; approximately 6 percent of low-income uninsured children meet this definition.

By definition, then, CSHCN have health care needs that exceed those generally required by typical children. Moreover, considerable research has shown, and Federal policy has endorsed, the need for services for CSHCN that are comprehensive, coordinated, community-based, and family-centered (MCHB, 1999). That is, services should address the full range of children's and families' needs in a coordinated fashion, should provide services in a child's community, and should involve families in program design and policy-making.

¹ Alternatively, states may set CHIP eligibility standards at 50 percentage points above their previous Medicaid eligibility levels for children, if that would produce a higher eligibility standard. States may also disregard income for even higher effective eligibility levels.

The design of such systems of care in the context of SCHIP presents a challenge. States may use SCHIP funding to expand Medicaid, to establish a separate state insurance program for children, or a combination of the two. A Medicaid expansion offers enrollees all of the benefits of that program, including the full EPSDT benefit package, unlimited services without copayments, and an entitlement program. However, with millions of potentially eligible children unenrolled, low rates of EPSDT screens, and widespread concern about access to and quality of care, Medicaid has not lived up to its promise for children.

The option of a separate state program provides states with the flexibility to design programs in new ways by attracting new providers, developing new delivery systems, and using innovative strategies to improve access. However, separate state SCHIP programs may have capped budgets, which can support only a limited number of enrollees; benefit packages may limit the amount, duration, or scope of specific services and may exclude certain services altogether; and they may impose cost-sharing requirements, including premium payments and copayments for services. All of these provisions may differentially affect children with chronic illnesses and disabilities, as they are most likely to require large numbers and a wide range of services. Thus, the challenge for states who choose this option is to use this flexibility to design programs that are comprehensive and meet children's needs.

This study addresses this issue by examining five states' SCHIP programs in detail. The purpose of the study was to examine alternative models of serving CSHCN under SCHIP to assess their ability to meet children's needs. The five states chosen for the study—California, Connecticut, Florida, North Carolina, and Pennsylvania—had all developed separate state SCHIP programs or combined approaches, and all had made some attempt in the design of their SCHIP programs to assure access to a full range of services for CSHCN.

These programs were structured in a variety of ways, or models. We examined these programs in order to assess alternative models' mechanisms for:

- Identifying CSHCN among SCHIP enrollees;

- Designing benefit packages to meet the full range of needs of CSHCN;
- Developing service delivery systems to assure access to the range of providers needed by CSHCN;
- Assuring that services are coordinated;
- Structuring payment systems to support the delivery of comprehensive services to CSHCN; and
- Monitoring and assuring the quality of care provided under these systems.

To address these issues, we conducted in-depth case studies in each of the five study states. During a three- to four-day site visit in each state, we interviewed a range of informants on the state and local levels, including state Medicaid, SCHIP, and Title V officials; state legislative and Governor's staff members; representatives of managed care organizations; providers, including general and specialist pediatricians, community health centers, and Title V CSHCN program providers; and families of CSHCN enrolled in state insurance programs. These interviews were conducted using a standard set of protocols to assure consistency across sites.

This report presents a synthesis and analysis of the results of these case studies; a companion volume includes detailed case studies of each of the study states. The following section of this volume presents an analysis of our findings in each of the areas mentioned above: enrollment and identification of CSHCN; benefits; service delivery systems; coordination of care; payment structures; and quality assurance and monitoring. The final section presents our analysis of the lessons learned by the study states in the early months of SCHIP implementation.

II. Description of Models

As described above, five states were chosen for inclusion in this study because of the effort they had made to assure comprehensive coverage for CSHCN under their SCHIP programs.

Although all had chosen to develop SCHIP programs that were distinct from Medicaid, they differed in several important ways. Table 1 summarizes key characteristics of the study states and their SCHIP and Medicaid programs.

In addition to these demographic and program characteristics, each state exemplified a distinct approach, or model, for serving CSHCN through their SCHIP program. These models are summarized briefly below, and will be discussed in detail throughout this chapter.

- **Wrap-arounds.** Both North Carolina and Connecticut based their separate state SCHIP programs on the state employees' benefit package; however, officials in both states were not satisfied that these benefit packages were sufficient to meet the needs of children with chronic illnesses. Therefore, they chose to cover additional, "wrap-around" services for children whose needs exceeded the SCHIP program's basic benefits. Under this approach, children are enrolled in SCHIP and receive all SCHIP-covered services through the mainstream system; however, children who meet a standard definition of CSHCN are also eligible for an additional package of clinical and support services. In North Carolina, the Health Choice program uses a fee-for-service payment system, while Connecticut's HUSKY program uses capitated managed care organizations to deliver basic services under SCHIP.
- **Service carve-out.** In California, the state had the advantage of a well-established system of care for CSHCN in the Title V-funded California Children Services (CCS) program. In addition, the state's Medi-Cal managed care program had established a precedent for separating the provision of primary and specialty care for CSHCN. Therefore, this arrangement was continued under Healthy Families, the state's SCHIP program. Under this model, all SCHIP-eligible children are enrolled in managed care plans for their primary care. Children with specific chronic conditions are also enrolled in CCS, which

provides all specialty services related to the qualifying condition. Thus, this package of specialty services is “carved out” of the managed care plans’ responsibility.

- **Specialty system.** Like California, Florida had developed a system for serving CSHCN under Medicaid that it expanded into the SCHIP population; this system was based on the state’s Title V CSHCN program as well. In this case, the state had developed a system of care called the Children’s Medical Services (CMS) Network, a county-based structure for providing both primary and specialty care to qualifying children through certified providers. This model, which had been in use for several years under the state’s Medicaid program, was extended to children with special health care needs whose family incomes qualified them for KidCare, the state’s SCHIP program. However, these children are not enrolled in mainstream plans at all; instead, children meeting a standard definition of CSHCN are identified at enrollment and enrolled in CMS for all of their care.
- **Mainstream model.** Rather than developing separate provisions for CSHCN, Pennsylvania officials have focused on providing comprehensive services to all children enrolled in the state’s PaSCHIP program. Therefore, under this approach, CSHCN are enrolled and served through the same system as typical children.

It should be noted that the study states are virtually alone in developing and implementing these models. Only a small number of additional states (including Alabama) have considered the development of a wrap-around package for CSHCN or developed specialized managed care systems for both Medicaid- and SCHIP-enrolled children (as has Michigan). Pennsylvania’s approach is more representative of the norm, as it is more focused on the broader goals of insuring the general population of children with a sound basic benefit package.

The following sections describe how the issues of enrollment and identification, benefits, service delivery systems, coordination, financing, and quality are addressed in each of these models.

Table 1. Characteristics of Study States

	California	Connecticut	Florida	North Carolina	Pennsylvania				
<i>Demographic characteristics</i>									
Region	West	Northeast	South	South	Northeast				
Total number of children, in thousands ¹	8,866	798	3,423	1,834	2,895				
Number of low-income uninsured children, in thousands ²	682	38	266	77	114				
Estimated number of CSHCN, in thousands ³	455	45	190	101	176				
<i>SCHIP Program Characteristics</i>									
SCHIP Program name	Healthy Families	HUSKY B	KidCare	Health Choice	PaSCHIP				
SCHIP CSHCN program name	CCS	HUSKY B Plus	CMS	Health Choice	none				
SCHIP program approach	combined	combined	combined	separate state program	separate state program				
Change in Medicaid/SCHIP income eligibility levels, by age	M	SSP	M	SSP	M	SSP	SSP	M	SSP
< 1 year		133% to 200%		185% to 300%		185% to 200%	185% to 200%		185% to 235%
1 through 5		133% to 200%		185% to 300%		133% to 200%	133% to 200%		133% to 235%
6 through 15		100% to 200%		185% to 300%		100% to 200%	100% to 200%		100% to 235%
15 through 18	15% to 100%	100% to 200%	56% to 100%	185% to 300%	28% to 100%	100% to 200%	100% to 200%	30% to 100%	100% to 235%
¹ Annie E. Casey Foundation, 1998 ² Ullman et al., 1998 ³ Newacheck, 1991									

A. Eligibility, Identification, and Enrollment

If a SCHIP program is to provide extra support or services to children with special health care needs and their families, the program must first have the capacity to define this target population, identify children meeting that definition, and link them with the systems (or providers) that have been established to address their special needs. This study revealed, however, that even among the handful of states that arguably have done the most thinking about how their SCHIP programs will meet the needs of CSHCN and have even incorporated specific program features for this population, this fundamental step of identifying and enrolling CSHCN has proven quite challenging and problematic.

To some extent, the inconsistency in defining CSHCN grows from the lack of a commonly accepted definition of a “child with a special health care need.” The research, policy, and medical communities have employed various definitions for children with chronic physical illnesses based on categorical program eligibility, the presence of a particular diagnosis or condition, an assessment of the degree to which a particular condition affects a child’s ability to function, and a demonstration of service use above that normally exhibited by children, among others (Stein, et al., 1993; Newacheck and Taylor, 1992). In three of the states we studied—Connecticut, Florida, and North Carolina—a very inclusive definition identical or similar to that adopted by the federal Maternal and Child Health Bureau is used: CSHCN are those who have or are at increased risk of chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally (McPherson, 1998). In contrast, California uses an extensive but, by definition, finite list of chronic illness diagnoses and congenital anomalies to qualify children for its CCS program, and Pennsylvania has adopted no special definition of CSHCN beyond the somewhat restrictive disability-based eligibility criteria set by the federal Supplemental Security Income (SSI) program. Thus, different states using different definitions of the target population have variable expectations regarding which and how many children may need special care under their SCHIP initiatives. Similarly inconsistent definitions of children with chronic mental health needs were observed in the study states, although three of the five tailored their behavioral health programs to address the needs of the narrower population of

children with clinically-diagnosed Serious Emotional Disturbance (SED).

Regardless of the definition used, it is notable that no state in our study has opted to implement any special outreach or marketing targeted to CSHCN and their families within the context of SCHIP. Rather, each has made it a higher priority to devote resources to broader SCHIP campaigns aimed at raising the general public's awareness of the importance and availability of low-cost health insurance for children in working poor families. Even Connecticut, which has gained considerable publicity in policy circles for its HUSKY Plus wrap-around benefit design, has chosen not to make Plus an explicit component of its outreach campaign. While other programs, such as Title V CSHCN programs, may conduct their own outreach efforts to identify CSHCN and refer them to insurance coverage and services, these efforts do not specifically promote the availability of SCHIP.

Rather than marketing specifically to this population, the states in our study have chosen to rely on various components of their systems of care to identify CSHCN and refer them to special services, when appropriate. However, regardless of the model implemented, it appears that each has struggled to operationalize its population definitions and institute systems through which CSHCN can be consistently identified among those children applying for or already enrolled in their SCHIP programs. Examples of states' varied approaches to identifying CSHCN are detailed below.

- **Mainstream Model.** In Pennsylvania, a unique Medicaid eligibility rule allows children meeting the SSI program's definition of disability to be considered an economic unit of one, thereby making virtually all such children, regardless of parental/household income, eligible for Medicaid coverage. With the more severely disabled population thus accounted for, according to state officials, the PA SCHIP program makes only a token effort to identify the remaining, less severely ill children who may be enrolling in SCHIP. Specifically, each SCHIP managed care plan administers its own program eligibility determination process and includes in its application form a single question: "Does your child have a special health care need?" Unfortunately, this open-ended question has "cast the net too broadly" according to state and managed care officials, resulting in affirmative responses from parents for everything from a routine need for eyeglasses to identification of life-threatening illnesses. Therefore, the results of this screening question are considered all but useless and, at best, may flag for physicians the need for a referral for specialty care.

- **Wrap-Around Models.** In both Connecticut and North Carolina, state officials rely largely on providers, insurers, and managed care officials to identify CSHCN who may benefit from wrap-around coverage. In Connecticut, no screening question is included in the HUSKY application form, nor is any screening for chronic illness included in the process followed by Benova—the state’s enrollment broker—when families are assisted with choosing a managed care plan. (Such questions are explicitly avoided due to the belief that families would be reluctant to discuss their children’s health status in the context of selecting a health plan due to fear of discrimination or denial of choice.) Rather, during health plans’ initial telephone calls to new enrollees, staff ask families about their children’s health status and needs. The identification of special needs triggers a referral to the plan’s case management unit, *not* either of the HUSKY Plus programs. Following a child’s enrollment, plans report that they only refer to HUSKY Plus once a child has exhausted his or her benefits under HUSKY B.

Similarly, North Carolina’s SCHIP application contains no screening question regarding a child’s health status or needs. Rather, all enrollees are given a *Health Choice Handbook* which includes, among many items, a 5-question screening form designed to identify CSHCN. Patterned loosely after the Questionnaire for Identifying Children with Chronic Conditions (QuICCC) (Stein, et al., 1997), this screen is quite broad and allows parents of children with birth defects, developmental disabilities, mental health problems, and other chronic conditions to identify their children. They may then call the state’s toll-free Special Needs Helpline, where staff are equipped to further assess the child’s needs and refer the family to services and supports in the community. It is important to note that this self-identification information is *not* forwarded to the SCHIP program’s fiscal intermediary—Blue Cross/Blue Shield—to assist it with reimbursement decisions regarding whether claims are to be paid out of the regular SCHIP budget or the special fund set aside for CSHCN.²

- **Service Carve-Out Model.** In California, once again, no screening questions regarding children’s health care needs are included in the *Healthy Families/Medi-Cal* application form. Rather, health plans’ primary care providers are expected to identify children with CCS-eligible conditions and refer them to that program for a medical eligibility determination and, if qualified, specialty care. Memoranda of Understanding between all health plans and local and regional CCS offices help ensure that providers are aware of CCS criteria and that these referrals take place. Unfortunately, given the model’s fully-capitated structure, this arrangement creates fiscal incentives for plans to refer all children suspected of having a qualifying special need to CCS where their care

² In this process, the *HealthChoice* fiscal intermediary—Blue Cross/Blue Shield—reviews all claims and determines if they are to be paid under SCHIP’s basic benefit package or out of the special pool of monies set aside for CSHCN. To date, as the fee-for-service structure in North Carolina creates no incentives to shift reimbursement responsibility among payment sources, few claims have been paid out of the special set-aside fund.

will be paid for on a fee-for-service basis, and not out of the plans' capitation rate.

- **Specialty System Model.** Florida's system of identification and referral combines components of several of the above systems. First, the *KidCare* application form includes a single screening question: "Does your child have a medical or developmental condition expected to last more than 12 months?" An affirmative response to this question results in a referral to CMS program staff who then conduct a medical eligibility determination. If eligible, the family is told of the special features of the CMS plan and encouraged to select it as their health plan. In addition, for children enrolled in mainstream health plans under *KidCare* who develop or are subsequently identified as having a chronic physical or mental illness or disability, health plans or providers can refer a family to CMS to see if they qualify. Again, a medical eligibility determination is conducted and qualified families are offered the option of enrolling in CMS. Similar to Pennsylvania, CMS officials note that the broad screening question on the *KidCare* application results in referrals of large numbers of children who don't ultimately meet CMS eligibility criteria—almost one-third of all applications have the "special needs" box checked, yet only about 40 percent of these children end of being found CMS-eligible. However, these officials were comfortable erring on the inclusive side and screening as many children as reasonably possible for the presence of special health care needs. As in California, this model gives plans an incentive to identify and refer all children who are potentially eligible for CMS in order to remove these high-cost children from their enrollee pool.

Adding another layer of complexity to the SCHIP eligibility process and, indirectly, to efforts to identify CSHCN, are the policies adopted by states to prevent the substitution of SCHIP coverage for employer-sponsored coverage. Title XXI requires states to address the potential for "crowd out," and most have done so through strategies such as cost sharing, employer subsidy efforts, ongoing monitoring, or the imposition of waiting periods whereby children must be uninsured for a minimum period of time before being allowed to enroll in SCHIP. Among our study states, "waiting period" policies varied considerably, as detailed below.

- Connecticut and North Carolina each impose six-month waiting periods on children applying for SCHIP coverage;
- California requires children to be uninsured a minimum of three months before being permitted to qualify for *Healthy Families*; and
- Neither Florida nor Pennsylvania impose any waiting period upon children applying for coverage under SCHIP, and instead monitor the extent to which children have or recently had employer-based coverage through information

gathered on the application.

During our site visits, key informants expressed the belief that waiting periods disproportionately affect CSHCN and may pose a significant barrier to their coverage under SCHIP. While a parent of a relatively healthy child may choose to go uninsured for a period of time before enrolling in SCHIP rather than continuing to purchase more expensive or limited private coverage, parents of CSHCN do not have this option; they cannot take the risk of dropping insurance for any time—even three months—given the potential harm that could come to their ill child during a gap in coverage. This constraint was described as particularly frustrating for parents who have had no previous choice but to purchase expensive coverage that is severely limited in scope. While many states allow exceptions to their crowd-out waiting periods (e.g., for families who have recently lost coverage because of a change in employment), none in our study made exceptions for children based on their health status, the presence of a chronic illness or disability, or the expense or limitations of existing coverage.

At the time of our site visits, each of the study states' Title XXI programs had been in place for between 12 and 15 months. As part of our analysis, we examined the programs' early experiences identifying and enrolling CSHCN, as reflected in their program data. What we found were a complex and disparate set of measures that appear to indicate that the states are struggling to enroll and serve as many CSHCN as they anticipated. More unequivocal was the finding that no state was seeing anywhere near the estimated 17 percent prevalence rate of CSHCN among their population of uninsured children that was published in recent research literature (Newacheck et al., 1998). Finally, at this time, it is difficult to ascertain whether one program model was performing more successfully than another in identifying and enrolling CSHCN. Specifically:

- **Specialty System Model.** In Florida, state officials expected to enroll approximately five percent of all *KidCare* eligibles into CMS. By November 1999, about 3,000 of 100,000 enrollees have been placed in CMS, a penetration rate of 3 percent.
- **Service Carve-Out Model.** In California, CCS officials anticipated that only between one and two percent of *Healthy Families* eligibles would be found to be CCS eligible. In fact, by August 1999, 2,000 of the program's 152,000 children—1.3 percent—were enrolled in CCS. No data were available on the

number of *Healthy Families* children that were qualifying to receive wrap-around behavioral services as a result of being diagnosed as having a serious emotional disturbance (SED); the state estimated a 3 percent prevalence rate of these children among their SCHIP eligibles.

- **Wrap-Around Models.** In Connecticut, state officials estimated that 8 percent of HUSKY B enrollees would be eligible for HUSKY Plus Physical, or 1,800 children. Of these, an estimated 400 children were expected to also have mental health needs triggering qualification for the HUSKY Plus Behavioral program. As of July 1999, the actual enrollment rates for these two programs were a surprisingly low 20 and seven children, respectively.

In North Carolina, by September 1999, only \$100,000 of the total \$3.5 million *HealthChoice* expenditures—less than 3 percent—had been debited from the special fund set aside to cover wrap-around expenses of CSHCN. An analysis by state officials of diagnoses included on *HealthChoice* claims, however, indicates that nearly 4,000 children in the program, or roughly 8 percent of all *HealthChoice* enrollees, have conditions that would qualify them as CSHCN.

- **Mainstream Model.** In Pennsylvania, no data are gathered and are therefore available identifying CSHCN among the population of SCHIP enrollees.

In sum, it appears that a number of factors are combining to challenge states in their efforts to identify CSHCN among their general population of uninsured children and refer them to the special services they may need. The lack of a commonly accepted definition of this population and a screening tool to operationalize this definition certainly hamper any attempts to systematically reach all CSHCN. Various financial incentives inherent in different SCHIP service delivery models also appear to affect the degree to which providers and managed care organizations identify and refer CSHCN to special programs. Waiting periods, designed to prevent crowd out, may also be posing a barrier to the enrollment of CSHCN. More fundamentally, however, early evidence in the study states suggests that CSHCN may be less prevalent among the general population of uninsured children than researchers originally anticipated; this fact, more than any other, may be at the root of what appear to be low rates of identification of CSHCN among SCHIP enrollees. Possible reasons for this lower-than-expected prevalence are discussed in the Lessons Learned section, below.

B. Benefits

The Balanced Budget Act of 1997 mandates the minimum benefits that must be covered under states' Title XXI programs. Although separate state programs offer considerable flexibility in determining the amount, duration, and scope of services covered, all states' benefit packages must provide coverage modeled on a "benchmark" plan (the Federal Employees Health Benefits Program, the coverage offered to state employees, or the state's largest commercial HMO), or coverage equivalent to one of these plans. Basic services that must be covered include inpatient and outpatient hospital services; physician, surgical, and medical services; laboratory and x-ray services; and well-baby and well-child care, including age-appropriate immunizations, and the plan must provide least 75 percent of the actuarial value of the benchmark package value for prescription drugs, mental health, vision, and hearing services.

By definition, then, SCHIP benefit packages are based on those typically provided under commercial plans to serve mainstream populations. This may cause concern for CSHCN for three main reasons:

- Children with special health care needs are likely to need health services beyond those covered in a basic children's insurance benefits package, such as increased physician monitoring, pediatric specialty care, mental health services, ancillary therapies, durable medical equipment (DME) or assistive technology, prescriptions, and care coordination, as well as habilitative and rehabilitative services. Although these services are likely to be covered under the benchmark packages, these packages often limit the amount, duration, and scope of services.
- A second set of benefits that may be absent from the benchmark packages is the family support and care coordination services often provided to CSHCN through Medicaid and Title V programs. These services, which families report to be essential in helping them coordinate their children's care and use resources in the community, are unlikely to be provided through mainstream insurance packages.
- A final concern in the determination of covered benefits is the definition of "medical necessity" included in plans' contracts. While Medicaid managed care contracts generally include an expansive definition intended to cover a wide range of habilitative and rehabilitative services, commercial contracts more often restrict coverage to services that are likely to improve an enrollee's health or restore function. These definitions would exclude a wide range of services needed to maintain function and promote development, even if a complete cure

is unlikely (Ireys, Wehr, and Cooke, 1999).

Under their SCHIP programs, the basic benefit packages offered to all children in the five states studied varied. Three states (North Carolina, California, and Connecticut) used their state employees' benefit packages as their benchmark, and two were existing state child health insurance programs grandfathered into Title XXI.³ In general, all provide coverage for inpatient and outpatient care, prescriptions, and physician, surgical, and laboratory services. Some benefit packages included additional, but limited, benefits for vision, hearing, podiatric and dental services. All did include some limitations and restrictions, however, many of which may be critical to CSHCN. These include the following:

- **Therapies.** All of the study states' basic SCHIP packages limit physical, occupational, and speech therapies. These ranged from a limit of 24 sessions within a 60-day period (in Florida's Healthy Kids program) to Pennsylvania's limit of 60 days of service in which "significant improvement" must be evident. Without a source of alternative or additional coverage, these limits can severely restrict the ability of children with chronic conditions to receive necessary habilitative care.
- **Mental health services.** All of the study states also impose specific limits on mental health services.⁴ Limits on inpatient care range from 15 days in Florida Healthy Kids to 90 days in Pennsylvania, and limits on outpatient visits range from 20 days in California and Florida to 50 in Pennsylvania. While wrap-around behavioral health benefits may be offered, they may be restricted to children who meet a strict clinical definition of Severe Emotional Disturbance. Children with ongoing behavioral health problems who do not meet this definition may not have access to needed services.
- **Inpatient care.** Florida Healthy Kids limits rehabilitative hospital stays for non-acute admissions to 15 days, and Pennsylvania's PaSCHIP program has an annual limit of 90 hospital days.
- **Skilled nursing and home health.** Florida and California limit skilled nursing services to 100 days per year, and Healthy Kids in Florida will approve home

³ Four of the study states chose to expand Medicaid as one component of their SCHIP program. As such, the benefits package for that component is, by law, governed by the Medicaid statute; therefore, it includes the full range of services covered by the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program.

⁴ In Connecticut, state legislation requiring parity between mental and physical health coverage went into effect on 1 January 2000, eliminating limits on mental health and substance abuse services under HUSKY B.

health care for skilled nursing services only. In addition, Pennsylvania allows only 60 home health visits per year under PaSCHIP.

- **Transportation.** Pennsylvania and Connecticut do not cover non-emergency transportation under their basic SCHIP programs, and North Carolina's program does not cover transportation services at all.

To remedy the gaps in the basic benefit packages, the additional benefits offered to CSHCN were generally designed to offer these children the full range of benefits available under Medicaid. While all of the study states except Pennsylvania offer additional physical and behavioral health services to CSHCN, the two benefit packages are generally quite distinct, with behavioral health services offered to a narrower population through a separate delivery system, sometimes using an entirely different model of care. The additional physical and behavioral health benefits covered in each of the models are described below.

- **Mainstream Model.** In Pennsylvania, all children are provided with a comprehensive benefit package which includes services such as hospice care, nursing services, home and community-based rehabilitation therapies, durable medical equipment and related remedial devices. The breadth of this benefit package is the result of considerable advocacy aimed at assuring that the benefits available to all children enrolled in PaSCHIP are comprehensive.
- **Service Carve-out.** In California, all services for CSHCN related to their qualifying condition are carved out of the standard Healthy Families benefits package and provided through California Children Services (CCS). Limits and exclusions in place under Healthy Families do not apply under CCS. The program covers diagnostic services, hospital and physician care, laboratory services, durable medical equipment, pharmacy, home health, orthodontic services, and HIV testing and monitoring. Physical and occupational therapy are also covered, along with follow-up services for high-risk infants and non-emergency transportation, as well as limited medical case management services and psychiatric services.

For children who are determined to be seriously emotionally disturbed, a wrap-around package of services, including a full range of individual, family, and group therapy services, intensive case management, day treatment, crisis intervention, and residential treatment, is provided through the county-based mental health system.

- **Wrap-around Models.** In North Carolina and Connecticut, CSHCN are provided with the state's standard SCHIP benefits and additional benefits are provided for special physical and behavioral conditions. In North Carolina, the wrap-around package for both physical and behavioral health needs offers

coverage equivalent to Medicaid, with two differences: Transportation is not offered, but two additional benefits, respite care and service coordination, are included. Connecticut's wrap-around program, modeled after the Title V CSHCN program, also provides Medicaid-equivalent coverage for physical health care needs, with the addition of respite care. For children with extensive behavioral health needs, a special wrap-around package of mobile crisis services, intensive case management, and in-home therapy is offered.

- **Specialized System.** In a specialized system, such as Florida's Children's Medical Services (CMS) program, CSHCN are enrolled in a separate managed care system specifically designed to meet their needs. The system provides the Medicaid benefit package and other services as medically necessary such as early intervention, respite, genetic testing, genetic and nutritional counseling as well as an enhanced package of behavioral health care services, including inpatient, outpatient, and residential treatment, as well as intensive case management, respite, and family support services.

The availability of family support services under SCHIP programs for CSHCN varied among the study states. As will be discussed in Section D, the extent of care coordination offered in the five study states ranged from a broad, community-based care coordination service offered through the Title V CSHCN programs in Connecticut and Florida to more traditional medical case management available in Pennsylvania and California (North Carolina's care coordination benefit for CSHCN is still under development.) Of the study states, only Connecticut offers additional family advocacy and support services to children with chronic physical conditions. These services were described by families to be essential in helping them to negotiate complex health care systems and to assuring that their children received all of the medical and community-based services they needed.

The issue of the definition of medical necessity in use under SCHIP appears to be particularly relevant in states such as Pennsylvania, which do not offer additional benefits to CSHCN, as these additional services tend to mimic Medicaid and to operate under more expansive guidelines. For children who do not receive additional benefits, however, the medical necessity issue can pose problems. In California and Pennsylvania, plans reported using the state Medicaid definition of medical necessity in the absence of a definition in the plans' contract. In Connecticut, at least some managed care plans reported that they used the standard definitions found in their commercial state health employees' benefit contracts for the SCHIP enrollees, in

the absence of guidance from state officials.

The efforts of four of the five study states (all but Pennsylvania) to make the full Medicaid benefit package available to CSHCN (sometimes with the addition of respite care and other family support services) emphasizes the importance of EPSDT's broad coverage for children with chronic conditions. However, the study states were much less likely to offer comprehensive support services, such as family advocacy and care coordination, which can be critical in helping families to use the services for which their children are eligible.

C. Service Delivery

Once insured, it is not only critical that children with special health care needs be covered for the full range of services they require, but also that they have access to a comprehensive, integrated system to provide these services. Given the range of conditions that children may experience, effective service delivery systems must be able to render a staggering array of services from appropriately qualified primary care, pediatric specialty, ancillary therapy, developmental, mental health, and support services providers. Furthermore, the systems in which these providers work must be arranged in such a way as to ensure that families can receive services in as coordinated, integrated, and seamless a fashion as possible.

To varying degrees, and in different ways, the states in our study have considered these issues and tailored their systems of care so that they might best serve CSHCN. The models we observed embody two alternative perspectives on the design of delivery systems: one is based on the expectation that the mainstream delivery system can develop and maintain the capacity to meet the full range of needs of CSHCN, while the other assumes that mainstream health systems cannot be expected to have such capacity, and that separate systems of care should be designed to work side-by-side with mainstream systems in order to address the specialized needs of CSHCN. While it is still too early to conclude which assumption is correct, it is possible to begin to identify the strengths and weaknesses that accompany each approach.

1. Serving CSHCN Through Mainstream Systems

Both Pennsylvania and North Carolina rely on their mainstream health care systems to serve all children, including CSHCN; Pennsylvania enrolls children in capitated managed care systems, while North Carolina serves SCHIP children through traditional fee-for-service arrangements.

- **Pennsylvania's Mainstream Capitated System.** In Pennsylvania, all SCHIP-eligible children, including CSHCN, are enrolled in fully-capitated managed care plans. Enrollment in these plans is mandatory except for those children living in rural northwest counties; thus, 95 percent of all SCHIP enrollees are served through managed care arrangements.

Importantly, the SCHIP service delivery network has been built upon the predecessor *Caring Foundation* programs and, thus, relies heavily on regional Blue Cross/Blue Shield plans—four of the seven MCOs serving SCHIP enrollees are affiliated with Blue Cross/Blue Shield organizations. The Blues networks are well accepted by providers and consumers alike and, as such, are considered to provide broad access to a full range of pediatric and other providers, including dentists (often through subcontracts with Delta Dental networks). Key informants consistently praised the managed care systems' ability to provide a primary care medical home to all children (once again, including CSHCN) and to extend appropriate pediatric subspecialty care to them.

Informants admit that the system's biggest flaw is that it makes no systematic effort to identify CSHCN and, instead, relies on the medical judgement of its participating providers to serve each child appropriately. Like most mainstream managed care systems, PaSCHIP's plans do not have strong links to nonmedical systems of care often used by CSHCN, like the state's Part C Early Intervention and special education systems, nor to the Title V program's *Special Kids Network* of community-based family support agencies. However, importantly, no key informant (including family and disabilities advocates) could report that they had heard of poor performance on the part of MCOs. To date, it appears that the service delivery systems in Pennsylvania are adequately equipped to meet the needs CSHCN enrolled in the SCHIP program.

- **North Carolina's Mainstream Fee-for-Service System.** In North Carolina, *HealthChoice* is built on a traditional indemnity model; all services for all enrollees are reimbursed on a fee-for-service basis and no managed care arrangements exist. Indeed, North Carolina's SCHIP statute actually prohibits the identification of a network of participating providers; thus, any provider willing to accept the SCHIP program's payments is free to participate and serve SCHIP enrollees. The so-called "wrap around" benefits are simply provided by the same providers already serving CSHCN, and the fiscal intermediary, behind the scenes and with the help of Title V program staff, determine if a given service is not covered by the standard package and thus should be billed to the

special fund set aside for CSHCN.

Fortunately, as the program is administered by the state employee health program through a contract with Blue Cross/Blue Shield, it is popular among providers and key informants report that access to care is consistently strong. However, state officials (and Title V officials in particular) admit that the indemnity approach offers little or no accountability with respect to guaranteeing children a medical home, or holding any individual or system responsible for organizing the care needed by CSHCN. Furthermore, it offers no obvious foundation upon which to build a care coordination infrastructure; state officials have recognized the significant need for a family-centered case management capacity, especially in this unstructured fee-for-service environment, and were working to develop alternative models at this writing.

2. Serving CSHCN with Specialized Systems of Care

California, Connecticut, and Florida each enroll all SCHIP-eligible children in mainstream managed care plans. However, for CSHCN, these systems are bolstered by the presence of additional, specialized systems of care that either work in tandem with or substitute for mainstream health systems. Importantly, these specialized systems represent, or are patterned after, those established by the states' Title V/Maternal and Child Health programs that serve CSHCN. In addition to the benefit of offering specialized networks of highly qualified providers to serve CSHCN, these models also help to assure ongoing financial support for specialized pediatric tertiary centers.

- **California's Specialty Carve-Out Model.** CSHCN eligible under California's *Healthy Families* program are enrolled in the same capitated managed care plans as all other SCHIP-eligible children; through these systems, they receive all of their primary and acute care. However, if these children are assessed and determined to have a qualifying condition, they are referred to CCS-paneled providers or CCS-sponsored Specialty Care Centers or Medical Therapy Units to receive all care related to their condition. These providers are reimbursed by the state on a fee-for-service basis.

This model is designed to address the commonly held belief that mainstream managed care organizations are not experienced with serving persons with disabilities, and that their specialty care is better handled by providers with particular expertise and experience with the population. In California, this translated into reliance on the well-established CCS network, built over many years by the Title V/Maternal and Child Health program. During our site visit, key informants consistently praised the high quality of this system and cited it as a strength of their SCHIP model (a model which duplicates the "carve out"

arrangement in place between Medi-Cal managed care systems and CCS).

Unfortunately, this system also suffers from some of the classic problems that typically surround service carve outs, namely, the “boundary” disputes between managed care and CCS providers over which system should be responsible for delivering and paying for particular services. Such disputes are exacerbated by payment arrangements that give health plans direct incentives to refer as many children as possible suspected of having CCS-eligible conditions to the CCS program.

- **Connecticut’s Wrap-Around Model.** In Connecticut, all HUSKY enrollees are required to enroll with a managed care organization and counseling on the selection of plans is provided by an enrollment broker. Plans, which are fully capitated, are responsible for rendering all services defined in the benefit package within their capitation payment. With regard to physical health services, when a child is determined to have exhausted his or her benefits in any given area, he or she is to be referred to one of two providers contracted to administer the HUSKY Plus Physical program—the Connecticut Children’s Medicaid Center in Hartford or the Yale Center for Children with Special Health Care Needs in New Haven. This wrap-around arrangement was designed to mirror that which has been used for several years for children who are dually eligible for Medicaid and Connecticut’s Title V/CSHCN program. Similarly, if a child exhausts his or her covered mental health benefits, a referral is to be made to the HUSKY Plus Behavioral contractor, the Yale Child Study Center.

Each HUSKY Plus contractor is staffed by a small team of clinicians, nurses, and family resource personnel. Importantly, these contractors are not responsible for taking over the care of HUSKY enrollees; rather, they are asked to manage, coordinate, and pay for services not covered by the basic benefit package, and specialty medical care or mental health services continue to be provided by the families’ existing caregivers. (Thus, this model has the advantage of offering the same network of trained specialists to typical children with short-term specialty care needs as to children with chronic conditions.) Given the expectation that families of CSHCN are likely to experience significant stress, the HUSKY Plus Physical contractors emphasize the provision of family support, counseling, and even respite care. Similarly, the HUSKY Plus Behavioral contractor arranges for the provision of such community-based services as intensive case management, in-home psychiatric and substance abuse treatment, and 24-hour mobile crisis services.

Unfortunately, it appears that the HUSKY/HUSKY Plus model has been undermined during its early months by unclear eligibility and referral criteria, and significant role confusion on the part of HUSKY health plans and Plus providers. Specifically, health plans officials report that they have interpreted the Plus program’s “wrap around” language quite literally and are only referring children to Plus when they have exhausted benefits (and are not, for example, referring all

identified CSHCN to Plus in order to receive potentially beneficial case management and family support). As the standard HUSKY B package is considered quite broad, it has typically covered children's needs well, and even CSHCN and their families have thus not benefitted from the social work and nursing support available from Plus contractors. Furthermore, key informants report that there exists a misconception among families and health plans that children referred to Plus contractors will have to switch providers and receive their wrap-around care from CCMC and Yale.

- **Florida's Specialty Managed Care Model.** Among the study states, Florida has most directly addressed what it believed were the structural weaknesses in its mainstream service delivery and financing systems and designed a separate, specialized managed care model to serve CSHCN. Building upon and enhancing its well-established Title V/Children's Medical Services (CMS) program, Florida has worked in recent years to recruit and credential a statewide network of primary care providers with experience (and willingness) to serve CSHCN, and used this network to augment its already established networks of specialty children's hospitals and regional CMS offices to create a separate capitated managed care system referred to as the CMS Network. (This network is available to Medicaid-eligible CSHCN as well.) As described in previous sections, *KidCare* enrollment staff attempt to identify CSHCN during the enrollment phase and offer them the option, up front, of enrolling in the CMS network. As a fallback, mainstream providers and health plans participating in *KidCare* are encouraged to identify CSHCN within their ranks and refer them to CMS if it appears that they could benefit from the specialty network it provides. Once enrolled, CSHCN are provided with access to appropriately qualified pediatric primary care and specialty providers, through a system that possesses a strong, family-centered case management capacity, and that has formal links to an array of other systems of care often needed by CSHCN, including Early Intervention, special education, and mental health. Indeed, on a pilot basis and for a small number of children diagnosed as having SED, CMS has for the first time been extended the responsibility for managing and paying for the delivery of children's mental health services. Broad consensus existed among key informants of all types that Florida's SCHIP (and Medicaid) delivery systems were stronger for the existence of the CMS program. Not only is CMS regarded as providing a stronger system of care for CSHCN, it also relieves mainstream managed care systems of the responsibility of caring for Florida's sickest children as well as the necessity of building specialty capacity that mainstream plans may be incapable of supporting.

In sum, it appears from our analysis and reports of key informants that every state's delivery system is doing an adequate, even good, job of providing for CSHCN enrolled in SCHIP.

Specialized service delivery arrangements such as the carve-out and wrap-around systems built into the California and Connecticut models, respectively, show considerable promise, yet have

to varying degrees struggled to achieve seamless service delivery with mainstream systems responsible for primary and acute care. At this early stage, the Florida CMS network appears to possess the greatest potential for providing the most integrated and comprehensive model of service delivery.

D. Coordination

Given the multiple and complex needs of CSHCN and their families, coordination of services can be a critical element in a state's SCHIP program. Indeed, the federal Maternal and Child Health Bureau (MCHB) has set national goals regarding the coordination of services for CSHCN, stating that delivery systems for CSHCN should be coordinated and provide multiple services from different providers as needed in a complementary, consistent and timely manner and in the sequence which best meets children's needs (MCHB, 1999).

Although care coordination is generally thought of as a service provided to clients and their families, coordination of services can take place at the program and policy levels as well. In fact, policy- and program-level coordination can greatly enhance coordination at the client level, by establishing links between agencies and instituting formal mechanisms through which to share resources among programs. Examples of these coordination efforts include:

- **Program level.** Sharing client information through a joint application or utilizing enrollment information to facilitate referrals between programs are examples of program-level coordination. Pennsylvania, for example, was in the process of developing a joint application between Medicaid and SCHIP at the time of the site visit; in addition, the state uses information from SCHIP enrollment and utilization records to make referrals to the state Title V CSHCN program as needed. Joint application forms are also in use in California, Connecticut, and Florida.
- **Policy level** coordination can include memoranda of understanding, agreements or policies regarding shared data or coordinated activities among administrative agencies. For example, in California and Florida, services for CSHCN under SCHIP are actually integrated into and provided through the Title V agency. Memoranda of agreement are in place in California to establish protocols for coordination efforts at the local level with county Title V programs and county mental health departments. North Carolina has also coordinated with Title V at the policy level to develop special provisions for CSHCN and Title V is involved

in the ongoing administration of the program.

Although most of the states studied had implemented or begun developing coordination systems and activities related to CSHCN, the study states vary in the extent to which SCHIP coordination efforts for CSHCN have evolved. Four of the five states studied included an explicit care coordination benefit for CSHCN in their Title XXI programs, but even these varied in focus and scope. Individual care coordination services ranged from medically-based case management, as provided by the CCS program in California, to more comprehensive care coordination, as offered through Connecticut's HUSKY Plus program. The latter benefit provides a broader range of coordination services, including helping to manage children's transition from Early Intervention to school, informing parents of services available in their communities, and advocacy for families within managed care organizations, in addition to the management of medical care. Of the study states, three (California, Connecticut, and Florida) currently provide some level of care coordination for CSHCN, and North Carolina is currently developing this benefit. The care coordination strategies observed in each of the SCHIP models are described below.

- **Mainstream model.** In Pennsylvania's mainstream managed care system, all services for CSHCN are provided through the managed care plan, and the primary care physician is responsible for providing or making referrals for all needed services. While "case management" is a function of the managed care plan, this role focuses on gatekeeping and utilization review, not on coordination of a broad range of medical and support services.
- **Service Carve-outs.** Care coordination is of particular importance in the carve-out model; the use of separate systems to deliver primary and specialty care offers great potential for gaps and duplication in services. Unfortunately, however, informants in California reported that no central care coordinator took on the role of coordinating all of a child's medical care. Medical case management services are available through the CCS program, but these coordinators have large caseload and tend to focus on coordinating only the child's referrals for care related to their chronic condition. More intensive case management services are available for children with severe emotional disorders, including linkages to community-based services, consultation, placement and development of a plan of care.
- **Wrap-around models.** Coordination is similarly critical in a wrap-around model to assure continuity of care between basic and wrap-around benefits. As mentioned above, the development of this benefit is in the planning stages in

North Carolina. The care coordination in Connecticut's wrap-around program is one of the broadest of our study states, as it encompasses medical, educational, and support services and aims to support the family as a whole in meeting the child's needs. These care coordinators are located in and paid by the two HUSKY Plus contractors, the children's hospitals who also provide these services under the state's Title V CSHCN program.

- **Specialized system.** Since a specialized system for CSHCN provides a single entry point for all SCHIP benefits for CSHCN, this approach minimizes the potential for gaps and duplication in services. Since these systems are designed specifically to meet the needs of CSHCN, this model may facilitate coordination of specialized care by a variety of service providers. In Florida, CMS nurses provide care coordination in the broad sense, involving schools, medical providers, transportation, family counseling, and social services. This was described by families to be an extremely valuable resource.

No consensus has yet been reached on the most effective model of care coordination for children with chronic illnesses and disabilities, and states' ability to coordinate and integrate these children's care varies widely under Medicaid managed care as well as SCHIP programs (Hill, et al., 1999). While the examples of care coordination found in the study states varied in intensity, the coordinators in all of these programs were housed and overseen by state Title V CSHCN programs. With effective coordination among agencies at the state and program levels, these programs can provide a resource to state Medicaid and SCHIP programs to offer comprehensive care coordination at the client level as well.

E. Payment

In any health care system, the structures established for paying insurers and providers, and the incentives inherent in them, can have important consequences for the delivery of care. For CSHCN, these structures are especially significant, as their care may be costly and they are particularly vulnerable to the incentive to withhold care under capitated systems. Therefore, advocates have encouraged the development of methods to adjust capitation rates for high-risk populations to assure that providers are adequately compensated for their care; however, these methods are still in the developmental stage (Hwang, et al., 2000).

All of the study states except North Carolina use capitated payments to contracted managed

care plans to finance services under SCHIP. The capitated payment rates are, in most cases, lower than those paid by the states' Medicaid programs, as the benefit packages are somewhat more limited. The plans may in some cases pass on risk to their contracted providers or may pay providers on a fee-for-service basis. In the case of North Carolina, the state passes per-member-per-month payments to the State Employee Health Plan which, in turn, contracts with Blue Cross Blue Shield for administrative services, but the state remains at risk and the providers are paid on a fee-for-service basis using rates that are generally higher than Medicaid's. No state adjusts payments to managed care plans to account for the cost of serving high-need enrollees, with the exception of Florida, which provides a separate capitation rate to CMS that is approximately ten times the Healthy Kids/MediKids rate for children of the same ages.

The payment structures for serving CSHCN varied based on the model of care used to serve this population, and issues arose that were particular to each model. These issues are discussed below.

- **Mainstream model.** Of course, in a capitated mainstream model, plans are subject to the traditional incentive to limit services to CSHCN. In Pennsylvania, it is impossible to monitor the use of services by CSHCN because the system lacks a consistent method by which to identify them in claims databases. However, the families and advocates interviewed in Pennsylvania did not report that care was being withheld, and plans and providers did not report problems of adverse selection.
- **Wrap-around models.** In both North Carolina and Connecticut, providers of wrap-around services are paid on a fee-for-service basis. In North Carolina, these services are provided through the same delivery system as services in the basic benefit package. In Connecticut, two contracted agencies coordinate and pay for the wrap-around services in the HUSKY Plus Physical and Behavioral packages; physical health services are provided through the contracted Title V CSHCN providers and behavioral services through a network developed by the Yale Child Study Center. In a fee-for-service system, new networks of wrap-around providers (such as the HUSKY Plus Behavioral network) face the challenge of generating a flow of funds that is sufficient to support their infrastructure, which may include new staff or expanded hours. Because enrollment may be low in the initial months of implementation, start-up funding may be needed to assure the providers' fiscal viability.
- **Service Carve-outs.** In California, providers who serve CSHCN through the

CCS program are paid on a fee-for-service basis, while managed care plans receive capitated rates for the provision of primary preventive and acute care. This structure creates an incentive for plans to reject as many claims as possible in the hope that CCS will cover them, and requires providers to coordinate billing between the two payment sources. The experience with this approach in California shows that it can lead to confusion, delays, and frustration on the part of providers, as many Healthy Families plans routinely deny claims for pediatric specialty care pending a referral to CCS, and the providers must often receive a denial from one payer before the other can be billed. The need to clearly delineate the responsibilities of each payer is critical to any carve-out system, and the effect of not doing so is often felt most acutely by providers.

- **Specialized system.** A capitated specialized system of care for CSHCN carries its own risks. In general, the benefit of capitation lies in its ability to spread risk (and cost) across a population with widely varying levels of need; that is, the capitation payments for healthy enrollees subsidize those of heavier users of services. In a specialized managed care program for CSHCN, there is less variation in the level of need across the enrolled population, so it becomes more important that the capitation rates be adequate to meet each enrollee's needs. Since few state programs have experience setting capitation rates for CSHCN, this approach is risky. In Florida, where the CMS Networks have been in operation (on a fee-for-service basis) for many years, the state had sufficient data to set rates, and the rates established for the capitated program appear to be adequate. It is also important to note that in Florida, it is the state CMS program, not the individual county agencies, that is at risk; therefore, risk is spread across the entire state's CMS population, and the agency is protected by the considerable variation in the needs of its enrolled children.

Another payment issue involves the mechanisms for paying primary care providers who serve CSHCN. In several states, primary care providers discussed the challenge involved in providing comprehensive services to CSHCN under existing rate structures that do not compensate them for the added intensity of these children's needs. One model emerged for enhancing the rates paid to primary care providers for serving CSHCN:

- Alameda Alliance for Health, in collaboration with the Center for the Vulnerable Child at Oakland Children's Hospital, has developed a set of criteria for identifying high-risk children, including both physical and psychosocial risk factors. Providers may receive an additional \$15 for serving children identified as having "moderate needs" and an additional \$30 for children identified as having "high needs" using this form. These rates were selected somewhat arbitrarily, but analyses are currently being conducted to determine the actual costs of providing primary care to CSHCN.

Another important element of many SCHIP programs is their requirement of financial

participation on the part of families. SCHIP programs are permitted more flexibility to require cost-sharing, in the form of both premium payments and co-payments for services. Three of the five study states (North Carolina, California, and Florida) charge premiums for the SCHIP program. These fees range from \$15 per family per month in Florida to a maximum of \$50 per family per month in Connecticut. None of the states waives the monthly premium for CSHCN. Rather than charge a monthly premium, North Carolina charges an annual “enrollment fee” of \$50 per child up to a maximum of \$100 per family. This was not reported to be a problem for families of CSHCN, as many are accustomed to large out-of-pocket expenses for their children’s care. The only state in which the premium was reported to cause a problem for CSHCN was Florida, where CSHCN are covered through the CMS Network. Since many enrollees had previously received services through this network at no cost, convincing them of the value of signing up for the SCHIP program (at a cost of \$15 a month) was reported to be a challenge.

Co-payments are more likely to affect CSHCN differentially, as these children use services with greater frequency than typical children. Of the study states, only Pennsylvania did not charge any copayments for services. The remaining states did charge co-pays of \$3 to \$5 for office visits and prescriptions, and some had additional co-pays for emergency care and dental and vision services. These fees were waived for services for CSHCN in all of the study states; however, the breadth of the waiver and the potential impact of the co-payment structure on families of CSHCN varies depending on the model used.

- **Wrap-around models.** In North Carolina and Connecticut, where special services are provided for CSHCN through a wrap-around model, families are still charged the standard co-payments (up to any defined limits) for all primary and specialty services provided through the mainstream system. (In Connecticut, these limits are set at \$650 per family with incomes of 185-235 percent of FPL and \$1250 for families with incomes between 235 and 300 percent of FPL.) Because CSHCN are particularly likely to use high levels of service, they will still be disproportionately affected by co-pays under this model.
- **Service carve-out model.** In California, the carve-out system provides only services related to the qualifying condition, so families are charged copayments for all other primary and specialty care. (Co-payments are waived for preventive services in California.) CSHCN may be no more likely than typical children to use acute services unrelated to their qualifying condition, so although co-

payments may be charged, they are less likely to be a particular burden to families of CSHCN under this model.

- **Specialty system.** In Florida, where all primary and specialty services are provided through a separate system, families of CSHCN are charged no co-payments for any services.

Therefore, it appears that only the specialty system or a mainstream model with no cost-sharing requirements completely insulate families of CSHCN from the imposition of co-payments. Of the other approaches, the wrap-around model is more likely to create cost burdens for families, especially if they must first exhaust a basic benefit package before gaining access to wrap-around services. (Of course, all children enrolled in SCHIP are protected from extreme financial burdens by the limit of 5 percent of family income.) Perhaps because of the low number of children enrolled in these programs, cost-sharing structures were not reported to be a major burden or a deterrent to the use of services. The actual impact of co-payments on children's use of services should be investigated further through comparative analyses of encounter data for children of similar ages and diagnoses in different service delivery and financing models.

F. Quality Assurance and Monitoring

A critical element of any health care system that serves children with special health care needs is a strategy to monitor and assure the quality of care provided to these children. Because CSHCN are particularly vulnerable to the incentives inherent in managed care, oversight is needed to assure that these children are receiving appropriate, high-quality, comprehensive care. However, the task of monitoring the care provided to this population is complicated by the relatively small number of CSHCN among most plans' enrollees, the varying natural history of chronic diseases, and children's changing developmental status. Therefore, the science of quality monitoring has not yet produced a definitive set of indicators with which to monitor quality for CSHCN; nonetheless, professional consensus has produced general approaches to monitoring the structure, process, and outcome of care for this population, and specific indicators are currently being developed and tested (Bethell, et al., 1999; Epstein, et al., 1998). In addition to these national efforts, individual state Medicaid agencies, Title V programs, and managed care organizations are also developing their own strategies for collecting and analyzing

data for quality monitoring.

State Medicaid managed care contracts often include standard quality assurance provisions such as the collection of encounter data from plans, the National Committee for Quality Assurance's HEDIS indicators, and the Consumer Assessment of Health Plans Survey (CAHPS). For their SCHIP programs, however, quality monitoring provisions are less consistent. In Connecticut, for example, although state officials plan to use indicators under HUSKY B similar to those monitored under Medicaid (HUSKY A), they are not collecting encounter data from managed care plans. State officials reasoned that, since the SCHIP program was intended to resemble a private insurance product, they should impose less onerous reporting requirements on the program's contractors. However, this greatly limits their ability to develop new indicators and monitor the provision of care to sub-populations. In California, the current Healthy Families model contract contains two monitoring requirements: plans must submit HEDIS 3.0 measures as well as the number of children who receive a health assessment within 120 days of enrollment. Other states, such as North Carolina and Florida, are designing satisfaction surveys and evaluative studies specific to their SCHIP programs rather than using the standard instruments in use under Medicaid.

In some cases, the study states did not incorporate quality measures or monitoring strategies specific to the population of CSHCN into their quality assurance approaches, although state officials indicated that this was on their agenda for the future. In Pennsylvania's mainstream model, state officials indicated that, while a range of mechanisms was in place to monitor the provision of primary and preventive care under PaSCHIP, they considered monitoring of the care provided to CSHCN to be the responsibility of the contracting plans. In Connecticut, a strategy for monitoring the care provided under HUSKY B Plus had not been developed after a year of implementation. In California, MRMIB had no immediate plans to monitor care provided to CCS enrollees under Healthy Families, although individual managed care plans were conducting their own population-wide and disease-specific studies.

In three of the study states, special efforts were under way to monitor, evaluate and assure the quality of care provided to CSHCN under SCHIP programs. These included the following:

- North Carolina’s Department of Public Health uses a range of approaches to monitor the care provided to CSHCN enrolled in Health Choice, including a family survey; a series of reports on the utilization of specific specialty services, the cost of services provided to CSHCN by diagnosis, and the number of CSHCN who receive care coordination; and a review of all denied claims for CSHCN. These reports are requested and reviewed by DPH’s Children and Youth Section (the state Title V agency) and the Commission on Children with Special Health Care Needs established by the Health Choice authorizing legislation and staffed by DPH.

- In Florida, the Institute for Child Health Policy (ICHP) at the University of Florida is taking the lead in developing a quality assurance strategy for the CMS program. Under a grant from the federal Maternal and Child Health Bureau, ICHP researchers are working in partnership with CMS officials to monitor children’s use of services under CMS. Indicators to be tracked in this pilot study include use of and expenditures for inpatient, outpatient, and emergency services; hospitalizations for ambulatory care-sensitive conditions (such as asthma and diabetes); the relationships among enrollment, disenrollment, and service use; and family satisfaction and its relationship to the use of services. The indicators and monitoring systems developed under this pilot study will then be tracked and used over time by the CMS program.

- In California, 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.) In addition, the CCS program conducts an annual family survey. On the local level, the Alameda County Committee on Children with Special Needs has developed a set of indicators specific to children with congenital heart disease and asthma, but these have not yet been consistently implemented by the participating plans.

These three states all represent different models of caring for CSHCN under SCHIP: one uses a wrap-around model, one a service carve-out, and one a specialized system of care. It appears, therefore, that the development of specialized quality monitoring approaches is related less to the model in use by the state than to the agency with responsibility for oversight of the program on the state level. In all three of the states discussed above, the state health departments, specifically their maternal and child health agencies, have significant responsibility for overseeing SCHIP services for CSHCN. In the other study states, public health agencies are not formally involved in this activity.

Thus, while quality monitoring efforts under SCHIP are less consistent and less sophisticated than those in place under Medicaid, provisions for quality assurance for CSHCN are better

developed in those states in which the public health agency has responsibility for them. Our findings indicate that the direct involvement of the state public health agency can help to assure that the quality of care provided to CSHCN receives attention within the overall SCHIP monitoring strategy. Specifically, the state MCH agency is often particularly well suited to this task, as it has both statutory authority for assuring the health of all children as well as expertise in the structures and processes of care that contribute to comprehensive, coordinated services for CSHCN.

III. Lessons Learned

In designing the State Child Health Insurance Program, policymakers' primary goal was to extend broad coverage to low-income children, most of them in working families, who did not have health insurance. Therefore, the SCHIP program was designed to provide basic coverage to as many children as possible, not to provide specialized services to children with complex medical conditions. Nonetheless, officials in several states understood that children with chronic conditions and disabilities were likely to be eligible for SCHIP, and that a mainstream health insurance program was unlikely to be sufficient to meet their needs. Specifically, traditional insurance products may not provide the breadth of benefits, provider networks, and coordination of primary, specialty, and support services needed by children with special health care needs and their families. Therefore, four of the five study states worked from the start to enhance their SCHIP programs to assure that the needs of eligible CSHCN were met; the fifth, Pennsylvania, added critical services to its benefit package after a year of implementation to ensure that coverage was adequate.

These five states used different models to deliver and finance the care of CSHCN enrolled in SCHIP. However, several common themes emerged from their efforts that supported the successful design and implementation of their SCHIP models. These lessons, which may guide any state that attempts to design specialized services for CSHCN in the context of SCHIP, include the following:

- **Recognition of the need for special provisions.** First, state officials understood that children with special health care needs are present in all economic groups. They knew that they could not assume that these children would necessarily be eligible for Medicaid or SSI, and they recognized that special provisions would be needed to serve these children adequately under SCHIP.

- **Establishment of screening mechanisms.** The first step in developing a system to serve CSHCN under SCHIP is the establishment of a mechanism through which to identify these children. To be sure, these systems are still in the developmental stages, and providers, plan administrators, and state officials are still learning how to design effective ways to screen children for special needs that successfully identify the children who need special services. However, all of the study states have made some effort, through questions on the SCHIP application form or guidance to managed care plans and providers, to screen SCHIP enrollees for special health care needs.
- **Provision of enhanced benefits.** The major contribution of the study states' efforts to serve CSHCN is the coverage of enhanced medical and behavioral health benefits, often with the addition of support services, to children for whom traditional benefits are insufficient. In four of the five study states, the standard SCHIP program's service limits do not apply to children identified as having special health care needs, essentially giving these children access to the full Medicaid/EPSDT benefit package. In addition, three of the five states offer additional support services, such as care coordination, respite care, family support groups, and advocacy to families of eligible children, benefits that were particularly appreciated by their recipients.
- **Use of innovative delivery systems.** Several of the study states chose to provide some or all services for CSHCN through delivery systems distinct from the mainstream plans and providers used by SCHIP enrollees. In these cases, states understood the importance of clearly delineating the roles and responsibilities of each system. While several states were still struggling in the first year of their programs with the implementation of these distinctions, officials recognized the importance of clear lines of communication and explicit agreements outlining the contributions of all participants in the system.
- **Collaboration with Title V.** In developing and implementing their SCHIP programs for CSHCN, four of the five states relied on systems and infrastructures developed under their state Title V CSHCN programs. The involvement of Title V staff and systems took many forms, including ongoing involvement in program planning and oversight, provision and coordination of services, credentialing and management of providers, and responsibility for quality assurance and monitoring. In general, the study states recognized that their Title V programs had developed an infrastructure to serve CSHCN; have staff, including care coordinators and family advocates, who know the needs of CSHCN and their families; and possess experience and expertise in monitoring and assuring the quality of care provided.
- **Family involvement.** In many cases, an integral part of the involvement of Title V in system planning and implementation is the involvement of families of CSHCN in the design and oversight of the system. The contribution of families through participation in advisory groups (as in Florida) and in key staff roles (as

in Connecticut) can clearly be seen in the ultimate development of programs that recognize families' needs.

- **A focus on quality.** Finally, several of the study states were beginning to focus on assessing the quality of care provided to CSHCN. Again, while these quality assurance strategies were often in the developmental stages, they reflect the states' commitment to the care of CSHCN.

Despite the positive ingredients found across the study states, they also faced significant challenges in effectively reaching, enrolling, and serving CSHCN in their programs. While some of these challenges may reflect the natural growing pains faced by any new program, others are more directly related to the specific models chosen by the states. These challenges included the following:

- **Outreach and enrollment.** Outreach and enrollment of eligible children is a challenge for SCHIP programs generally, and states are learning that ongoing, sustained outreach is needed to assure that the families of potentially eligible children understand the need for health insurance for their children and are aware of the SCHIP program. These outreach campaigns, however, do not specifically target families of CSHCN, for several possible reasons: since children with chronic illnesses are likely to receive health services somewhere, population-based outreach may not be the most efficient way to locate these children. Instead, hospitals and Title V CSHCN programs in many states are searching their patient records for self-pay patients and referring them for coverage when they come in for services. In addition, however, states may be reluctant to advertise SCHIP as a program for children with disabilities for fear of encouraging adverse selection or crowd-out. Whatever the reason, the states have all found that the proportion of children enrolled in their SCHIP programs identified as having special needs rarely comes close to their original estimates, and none even approach the 17 percent estimated in national studies.
- **Defining and identifying CSHCN.** Four of the five study states (all but Pennsylvania) had made some effort to define the population of CSHCN for purposes of enrollment in carve-out, wrap-around, or specialty systems. However, operationalizing these definitions and using them to identify and refer eligible children has proven challenging. For example, while Connecticut based its program on the broadest definition of CSHCN, it has shown the least success in actually enrolling children into its wrap-around program in the first year of its operation. This is likely to be due to the difficulty of operationalizing its eligibility criteria, which were based on the MCHB's definition of CSHCN. Other states with more clearly-defined criteria, such as California and Florida, have had more success in enrolling children into their special programs; however, these criteria, whether based on diagnosis (like California's) or service need (like Florida's), inevitably exclude some children. Thus, it is likely that some children

in these states with mild or moderate special health care needs, or with diagnoses that are not on the defined list, are not enrolled in the special programs designed for them.

- **Access to special services.** The converse of the states' difficulty identifying children with special health care needs among SCHIP enrollees is the difficulty these children may experience gaining access to the specialty and support services they need. In both wrap-around and carve-out systems, children who are not identified as meeting the state's definition of CSHCN are denied access to clinical and support services beyond those covered by the basic SCHIP benefit package. Even in Pennsylvania's mainstream system, the state's inability to identify CSHCN among PaSCHIP enrollees limits their access to other community-based systems of care, such as the Title V Special Kids Network, from which they might benefit.
- **Coordination of care.** Because of the range of services needed by many CSHCN, the assistance of a care coordinator (sometimes known as a case manager) can be essential in assuring access to needed medical care, therapies, and family support services. However, few states offer a comprehensive care coordination benefit to CSHCN. Of the study states, those that come the closest are Florida and Connecticut, where community-based care coordination is provided by nurses and social workers employed by or under contract to the states' Title V CSHCN programs. Even in these states, however, the physical and behavioral health services used by CSHCN are generally completely distinct, with no single coordinator given responsibility for managing all of a child's care. Moreover, the model in which coordination is most critical, California's service carve-out approach, did not include the services of a coordinator who could keep track of both the basic and the specialty care needs of their clients.
- **Providing comprehensive mental health services.** While several of the study states had taken a broad view in their definition of children with special physical health care needs, most offered additional behavioral health care services only to a narrow population of children with a clinical diagnosis of severe emotional disturbance (SED). However, many children with physical health conditions have mental health needs as well, and many children have behavioral problems that do not meet the definition of SED. Moreover, the basic SCHIP programs of all of the study states include limits on mental health services. Thus, many children in need of such wrap-around services as family counseling, respite care, in-home therapies, and crisis services may not have access to them under these programs.
- **Monitoring and assuring quality.** While the study states had made admirable efforts to develop systems of care for CSHCN, few of them had clearly defined strategies for monitoring these systems to assure that these provisions were working effectively. While several states had such systems in development, few states were able to describe a current strategy for monitoring the effectiveness of identification and referral system, access to primary and specialty care, quality of

care received, or family satisfaction with the SCHIP program.

The structure of each of the models studied emphasized these strengths and weaknesses to different degrees. The major advantages and disadvantages of each of the models are summarized below.

- **Wrap-around models.** Two of the study states, Connecticut and North Carolina, chose to augment their basic SCHIP benefit packages with wrap-around physical and behavioral health benefits for children with special health care needs. This approach has the advantage of offering a rich benefit package to CSHCN: both study states offered the equivalent of the full Medicaid benefit package to eligible children, with the addition of care coordination and respite care for their families. The major disadvantage of this approach is its reliance on health care providers and insurers to identify and refer children to the wrap-around programs. In both states, these programs had served far fewer children than anticipated, due mainly to the difficulty of identifying eligible children and assuring consistent referrals.

The incentives inherent in alternative payment systems are particularly critical in a wrap-around model. In North Carolina's fee-for-service system, the insurer's case managers have no incentive to refer claims to the special CSHCN fund for payment, as their payments are not capitated. However, because the program as a whole operates under a limited budget, the case managers' lenience in approving claims risks expending the base SCHIP budget unnecessarily, leaving the special fund relatively untouched. Connecticut's capitated system has balanced its incentives more successfully: because the managed care plans are capitated for the base benefit package, they do not gain anything by referring children to the wrap-around program, as the program only covers services the basic SCHIP benefit package does not.

- **Service carve-outs.** In California, policymakers chose to preserve the existing system of care available to CSHCN through the Title V program by using the service carve-out approach already in place under Medi-Cal's managed care program. The major advantage of this decision is that it provides qualifying children with access to a long-standing program of proven quality, while preserving the flow of funds to providers, particularly tertiary providers, who provide essential services for children with complex conditions. Like the wrap-around model, this system also requires that providers identify and refer eligible children to the carve-out system; however, in California's case, the Title V program is well-established and familiar to providers, so this has not posed the challenge that it might with a completely new system. The major disadvantage evident in California's program appears to be the lack of coordination between primary care, which is provided through mainstream managed care plans, with specialty care, which is provided through the carve-out system. In addition, the carve-out system has been frustrating for providers, who must determine which

program to bill for each claim.

- **Specialty systems.** Florida also chose to apply the model in use under its Medicaid managed care program to SCHIP, enrolling qualifying children in the CMS Network rather than in mainstream managed care plans. This approach works best if eligible children can be identified at enrollment whenever possible, so children do not later have to change plans and providers entirely, and therefore avoids the pitfalls of identification and referral by providers. In addition, because this model provides primary, specialty, and support services through a single program, it shows the greatest likelihood of offering comprehensive, coordinated care that is designed to meet the needs of CSHCN. Capitated payment can prove to be a challenge in a specialty model, however, as risk must be spread across a population of high-risk children. In Florida, state officials have addressed this problem by assigning risk to the state CMS program, not individual county programs, and by offering relatively generous capitation rates.
- **Mainstream model.** Finally, Pennsylvania chose to address the needs of CSHCN by enhancing the mainstream SCHIP program, thus making additional benefits available to all eligible children, regardless of their conditions. This approach has the benefit of simplicity and equity; benefits such as durable medical equipment and rehabilitative therapies can be important to children with short-term acute as well as chronic conditions. However, by choosing the mainstream model, the state sacrifices the ability to identify CSHCN within the SCHIP enrollee population, to refer them to resources in the community, and to monitor the quality of their care.

Again, the policy goal of SCHIP on the national level as well as in the states is to provide basic insurance to all low-income children. Therefore, the program's focus, even in the progressive states studied here, is not generally on the provision of comprehensive services to CSHCN.

While they offer promising models and useful lessons from which other states may learn, even these states are far from offering "best practices."

One issue that is particularly vexing to state officials and observers is the low number of children identified in these SCHIP programs as having special health care needs. As mentioned above, national sources estimate that as many as 17 percent of low-income uninsured children, the SCHIP target population, have a special health care need of some type, and 6 percent have a disability. However, none of the study states, even those who have cast the broadest net to screen and identify CSCHN in their SCHIP populations, have found CSHCN in anywhere near those proportions. In discussing this issue with key informants in the study states, several

possible explanations emerged for these results:

- **Outreach and identification have been unsuccessful.** As noted above, states' SCHIP outreach efforts rarely focus specifically on CSHCN, and their efforts to identify these children after they enroll have met with mixed success. Therefore, it is possible that children who need special services are enrolling in SCHIP and are simply not being identified and referred to the systems designed to serve them.
- **Programs need more time.** Three of the five study states (all but Florida and Pennsylvania) were still in the early stages of program implementation at the time of this study. It is possible that these programs and their screening and referral mechanisms simply need more time to reach full implementation; that is, while children may have enrolled in SCHIP programs, many might not yet have begun using services, and thus have not been available for screening and identification by plans or providers. Thus, as programs reach full capacity and children begin using their coverage more fully, the numbers of children with special health care needs enrolled in special systems should increase as well.
- **CSHCN are less likely to be uninsured.** A third theory would question the premise that CSHCN are as likely to be uninsured as other children of the same income level. Rather, some observers believe that children with chronic illnesses and disabilities are actually *less* likely than other children to be completely uninsured; because of these children's frequent needs and the cost of their care, working families will go to great effort and expense to get insurance of some sort for these children, even if it does not provide comprehensive coverage, while low-income children with the most severe needs may be eligible for Medicaid coverage through SSI. Therefore, those SCHIP enrollees who have milder chronic illnesses (such as asthma, for example) are likely to be less severely affected by their conditions and may not require the range of services and supports available under specialty and wrap-around programs. In fact, mainstream managed care programs may be well suited to provide coordinated primary and specialty care to these children and to manage their acute care needs.

This last theory, if true, raises a key question for the future of SCHIP and its approach to providing health care coverage for children. The intent of SCHIP to cover *uninsured* children is clear, and is evident in the policies in place in the states to prevent crowd-out and substitution of public for private coverage. This program is not intended to provide for *underinsured* children, those who have private insurance policies that are expensive or that do not meet their needs, and who are particularly likely to have special health care needs. However, SCHIP offers an attractive alternative for these children's families, as many are paying high premiums

for limited coverage; indeed, our site visits confirmed that families with insurance were often interested in SCHIP and were frustrated by waiting periods. Therefore, it is possible that SCHIP's attempts to prevent crowd-out disproportionately affect CSHCN.

This raises an important policy question: should SCHIP be used to offer children not just insurance, but *higher quality* insurance than they can purchase in the private market? If so, this could be effected either by exempting CSHCN from waiting periods, or by offering SCHIP as a secondary insurer to more limited commercial coverage for selected groups of children (as Medicaid does for all eligible children). While strategies such as these may not coincide with the original policy goals of SCHIP, they may provide new approaches to assuring comprehensive coverage for children with special health care needs.

Glossary

Capitation. A method of payment for health services in which a provider is paid a fixed amount for each person served, without regard to the actual number or nature of services provided to each person in a given period of time.

Carve-out. Exclusion of specific services from a health insurance benefit package.

Crowd out. Replacement of private health insurance coverage with publicly-financed coverage.

Children with special health care needs (CSHCN). Defined by the U.S. Maternal and Child Health Bureau as “children who have, or are at risk for, chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children generally.”

Early and Periodic Screening, Diagnosis, and Treatment Program (EPSDT). A program mandated by law as part of the Medicaid program. The law requires that all states have in effect a program for eligible children under age 21 to ascertain their physical or mental health and to provide such health care treatments and other measures to correct or ameliorate defects and chronic conditions discovered.

State Children’s Health Insurance Program (SSCHIP). Title XXI of the Social Security Act, which provides funding to states to provide health insurance to low-income uninsured children who are not eligible for Medicaid. Coverage may be provided through an expansion of the state Medicaid program, the establishment of a separate child health insurance program, or a combination of the two.

Specialty system. A system of health care designed and implemented specifically for children with special health care needs or other people with disabilities.

Supplemental Security Income (SSI). An income support program administered by the Social Security Administration for people who are 65 or over, blind, or who have a disability. Benefits are available to children in families with limited income and assets who have a physical or mental condition (or a combination of conditions) that results in “marked and severe functional limitations.” The condition must last or be expected to last at least 12 months or be expected to result in the child's death.

Title V. Codified as Title V of the Social Security Act, and also known as the Maternal and Child Health Block Grant, a program of grants to the states to assure the health of all mothers and children, including children with special health care needs. The block grant program requires that States match \$3 in funds or resources for every \$4 in Federal funds they receive,

and that a minimum of 30 percent of block grant funds be used to support programs for children with special health needs.

Wrap-around. A set of health care benefits provided in addition to a package of standard, or basic, benefits.

Internet Resources

For more information about the programs discussed in this report, resources are available at the following Internet sites:

California

Healthy Families

<http://www.healthyfamilies.ca.gov>

California Children Services

<http://www.dhs.cahwnet.gov/prp/cms/html/ccs.htm>

Connecticut

HUSKY

<http://www.huskyhealth.com>

Florida

KidCare

<http://www.floridakidcare.org>

Children's Medical Services

<http://www.doh.state.fl.us/cms>

North Carolina

Health Choice

<http://www.dhhs.state.nc.us/docs/hchoice.htm>

Pennsylvania

PaSCHIP

<http://www.insurance.state.pa.us/html/SCHIP.html>

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