kaiser commission on medicaid and the uninsured

SCHIP-ENROLLED CHILDREN WITH SPECIAL HEALTH CARE NEEDS: AN ASSESSMENT OF COORDINATION EFFORTS BETWEEN STATE SCHIP AND TITLE V PROGRAMS

Prepared for the Kaiser Commission on Medicaid and the Uninsured

Anne Markus, J.D., Ph.D.
Sara Rosenbaum, J.D.
Soeurette Cyprien
Center for Health Services Research and Policy
School of Public Health and Health Services
The George Washington University Medical Center
Washington, D.C.

January 2004

THE HENRY J. KAISER FAMILY FOUNDATION

kaiser commission medicaid and the uninsured

The Kaiser Commission on Medicaid and the Uninsured provides information and analysis on health care coverage and access for the low-income population, with a special focus on Medicaid's role and coverage of the uninsured. Begun in 1991 and based in the Kaiser Family Foundation's Washington, DC office, the Commission is the largest operating program of the Foundation. The Commission's work is conducted by Foundation staff under the guidance of a bi-partisan group of national leaders and experts in health care and public policy.

TABLE OF CONTENTS

ABSTRACT ..... **i**

EXECUTIVE SUMMARY **1**

INTRODUCTION **5**

THE TITLE V MATERNAL AND CHILD HEALTH SERVICES BLOCK GRANT PROGRAM **7**

MODELS OF COORDINATION BETWEEN SCHIP AND TITLE V **14**

STUDY STRUCTURE 14
STUDY RESULTS 15

DISCUSSION AND CONCLUSION **21**

APPENDIX (STATE-BY-STATE PROFILES) **24**

ENDNOTES **40**

ABSTRACT

The purpose of this study was threefold: (1) to describe the Title V Maternal and Child Health Services Block Grant program as it pertains to children with special health care needs (Title V CSHCN programs); (2) to explore the level of interaction and coordination between Title V CSHCN programs and separate SCHIP programs in terms of providing services to children with special health care needs; and (3) to assess the implications of state program choices for publicly-funded health insurance programs and pediatric health care.

The methodology consisted of a review of existing research findings on states' early experience with implementing the SCHIP program, an analysis of the coordination and benefit provisions of the state SCHIP plans filed with CMS, a written survey of Title V agencies regarding changes to their CSHCN program after SCHIP was enacted, and the creation of comparative tables of a core set of benefits frequently needed by CSHCN based on information compiled from the state SCHIP plans and the 2000 Edition of the "Directory of State Title V CSHCN Programs-Eligibility Criteria and Scope of Services" and validated by Title V agencies. All 35 states with separately-administered SCHIP programs were originally included in the study.

Key findings include:

- States have used the flexibility provided under SCHIP to adopt benefit packages that are generally less comprehensive than Medicaid. Although these benefit packages work well for the vast majority of children who are healthy, they can result in children with special health care needs facing gaps in needed services.

- A handful of states have used their Title V programs to attempt to fill the gaps in coverage for children with special health care needs created by scaled back SCHIP benefit packages. The vast majority of states, however, have not taken such steps.

- Even among the handful of states that have sought to coordinate their Title V and SCHIP programs to improve coverage for children with special health care needs, some of these children - particularly those with extensive behavioral health needs - are likely to find that it is difficult for them to navigate the system and, once they do, that they still face gaps in coverage.

In sum, the limitations on SCHIP benefits are likely to have a disproportionate and potentially significant effect on children with special health care needs. Although there are some exceptions, states generally have not used their Title V programs or other programs to fill effectively the gaps in care for children with special health care needs created by a scaled back SCHIP benefit package. These children thus face the limitations of the SCHIP benefit package with nowhere else to turn for needed specialty care.

EXECUTIVE SUMMARY

This Issue Paper, prepared for the Kaiser Commission on Medicaid and the Uninsured, examines states' use of the Title V Maternal and Child Health Services Block Grant Program to supplement or complement their separately-administered SCHIP programs in the case of children with special health care needs (CSHCN). Separately-administered SCHIP programs typically offer benefits that are more limited than those in Medicaid. They also tend to exclude or place limits on services that can be critical to CSHCN. Services, such as nonemergency transportation, care coordination, respiratory care, and personal care services, tend to be excluded altogether, while services, such as physical, occupational, and speech therapy, rehabilitation care, prescription drugs, vision, dental, and hearing care, hospice care, mental health and substance abuse services, and durable medical equipment, face serious limitations in scope, duration and amount. The prevalence of limitations and exclusions in benefit packages offered by separately-administered SCHIP programs raises the question of whether these programs have the ability to appropriately meet the needs of CSHCN and whether they provide supplementary or complementary services to these children, using Title V as a possible source of care.

The strategies that states use in providing for CSHCN who are enrolled in separate SCHIP programs and who thus are not entitled to the full range of Medicaid benefits is of particular importance given the high degree of current interest, as evidenced by the Administration's Health Insurance Flexibility and Accountability (HIFA) demonstration initiative and the President's proposed Medicaid reforms, in the issue of Medicaid benefit design flexibility. What approaches do states take in supporting SCHIP-enrolled CSHCN and their families? Specifically, what is the role played by state Title V programs, whose historic roots lay in great part in the provision of services to children with long term physical disabilities, and can these programs supplement adequately separate SCHIP programs' more limited benefit packages? What lessons can be learned for the coverage of children and adults with disabilities?

Title V is one of the nation's oldest health programs and represents a pivotal part of the beginning of the modern maternal and child health policy era. Enacted in 1935 as part of the original Social Security Act and codified at Title V, the legislation represented one of the very first state "grant-in-aid" programs, allocating federal revenues to states that agreed to meet the program's basic conditions of participation, which revolved around two main goals. The first was to assist states lessen the negative social and public health impact of the Great Depression through promotion of maternal and child health services and the development of a basic preventive and primary health care infrastructure for women and children. The second, and one directly tied to the terrible epidemic of poliomyelitis, was to assist states through grants to develop services for "crippled children." Today, some 27 million women and children and approximately one million CSHCN receive care through Title V programs.

Since its creation, Title V has grown from a $2.7 million program in FY 1936 to a $732 million program in FY 2002, and despite its relatively modest size, it has been revisited by Congress repeatedly over the years as new maternal and child health related concerns become evident. Even with the enactment of Medicaid in 1965, the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) program in 1967 (which simultaneously amended Medicaid and Title V to increase support for primary care) and SCHIP in 1997, Title V has continued as a

source of flexible funding that allows states to invest in the child health "infrastructure" for both basic and specialty care. At the same time, the fact that a series of public health financing programs simultaneously are focusing on low-income and special needs children raises important issues of coordination. Toward this end, the federal Title V and Medicaid statutes specifically require state Title V and Medicaid agencies, as a condition of federal funding, to coordinate their activities. And while the SCHIP statute and regulations require states to describe the procedures they will use to coordinate their SCHIP program with Title V programs, the Title V statute contains no coordination requirements between Title V and SCHIP similar to those imposed on Title V and Medicaid. In the context of SCHIP and CSHCN, state Title V agencies have the option to choose from three basic coordination strategies—technical assistance, outreach, and provision of services—alone or combined, in order to coordinate the administration of SCHIP and Title V to enhance services for CSHCN.

In this Issue Paper, we focus on states' use of Title V to provide services not covered by SCHIP in the case of special needs children. Our methodology consisted of the following approaches: a review of existing research findings on states' early experience with implementing the SCHIP program, which together covered a majority of separately-administered SCHIP programs (51%) and SCHIP enrollees (74%); an analysis of the coordination and benefit provisions of the 35 state separate SCHIP plans filed with CMS as of December 2000; a written survey of Title V agencies in the 35 states with separately-administered SCHIP programs conducted in 2001 regarding changes to their CSHCN program after SCHIP was enacted (response rate=51%); and the creation of comparative tables of a core set of benefits frequently needed by CSHCN based on information compiled from the state SCHIP plans and the 2000 Edition of the "Directory of State Title V CSHCN Programs-Eligibility Criteria and Scope of Services" and validated by Title V agencies (response rate=51%). Our main findings include:

1. **Program Design Phase—Models of Coordination between SCHIP and Title V.** Only six states were identified as having considered CSHCN during SCHIP program design and included Title V agencies responsible for this population in their discussion about what the program should look like. These states fall into three basic models of addressing the needs of CSHCN in the SCHIP context: (1) the "service supplement" model, in which the state offers a basic benefit package resembling commercial insurance in its SCHIP program and supplements those basic benefits with "wrap-around" services that go beyond the scope, amount or duration of the SCHIP benefits (3 states); (2) the "specialty care carve-out" model, in which the state completely excludes certain specialty care services (e.g., private duty nursing) in its SCHIP program and has an existing specialty care carve-out program for CHSCN, which is incorporated into SCHIP (1 state); and (3) the "person carve-out" model, in which the state refers SCHIP-eligible CSHCN to a special, Title V administered managed care system or other integrated health care delivery system for CSHCN, which provides the full spectrum of services and is incorporated into SCHIP (2 states). In contrast, CSHCN were "not even on the radar screen" in the remaining states, i.e., the majority of states with separately-administered SCHIP programs, which appear to rely heavily on their existing Medicaid medically needy spend-down programs to provide services to CSHCN. For these states, any one of the three models could prove useful, especially the first one when there is no special Title V program already in place in the state.

2. **Program Implementation Phase—Improvements in Coverage.** Among the handful of states that adopted coordination strategies, state Title V contacts described a collaboration with state SCHIP agencies that not only started during the design phase of the separate SCHIP program but also continued well into its implementation. Changes to the Title V CSHCN programs occurred in the majority of these states following the implementation of the SCHIP program, but the type of change undertaken varied from state to state. Two states expanded coverage for certain services such as enabling transportation and vision care; one state transferred all of its Title V enrollees to the state's separate SCHIP program, and started focusing on underinsurance; and another state made the Title

V agency responsible for coordinating the additional benefits provided to CSHCN and monitoring the quality of care furnished. All of these changes represented improvements in coverage. By pursuing collaboration in both the design and implementation phases of separate SCHIP programs, SCHIP and Title V CSHCN agencies can increase the likelihood that CSHCN enrolled in SCHIP will receive needed care beyond what would be available through the basic SCHIP program.

3. **Program Implementation Phase—Gaps in Coverage.** Despite the improvements made to Title V CSHCN programs, our analysis suggests that three categories of services that are critical to CSHCN may lack sufficient coverage, even with the high level of coordination that exists between SCHIP and Title V in the study states, unless there is a good referral system to other sources of care that can provide these services. These three categories of services include: (1) oral health care; (2) mental health and substance abuse services; and (3) enabling transportation. Although dental care is covered by all states (with the exception of one Title V agency, which excludes it), it faces significant limitations in scope, duration, and amount both in SCHIP and Title V. Similarly, the majority of SCHIP programs limit coverage of mental health and substance abuse services, particularly those provided on an outpatient basis. In contrast, the majority of Title V agencies exclude coverage for inpatient and outpatient mental health services, and all agencies exclude coverage for inpatient and outpatient substance abuse services. More than half of the states justified their choice by explaining that another agency in the state covers these services negating the need for their agency to pay for these services or that the agency refers CSHCN in need of such services to other sources of care, e.g., a behavioral specialty care system. Because of the traditional emphasis of Title V on physical services, Title V CSHCN programs would not be expected to provide the full spectrum of behavioral services, especially since other agencies in the state are usually responsible for these services. On the other hand, because of the enactment of SCHIP and its somewhat limited coverage of behavioral health services, Title V agencies could presumably have made some adjustments for CSHCN enrolled in SCHIP who would need such services. Finally, in the case of enabling transportation, the majority of separate SCHIP programs exclude coverage of enabling transportation, while half of the Title V CSHCN programs exclude it altogether and a third cover it with limitations, with the exception of one state where the state SCHIP plan excludes coverage of enabling transportation and the Title V CSHCN program filled in the gap for SCHIP-enrolled CSHCN eligible for Title V services, as a direct consequence of the implementation of SCHIP.

Taken together, these findings have important implications for access to care by CSHCN in separate SCHIP programs but also for access to care by all children and adults with special needs who currently receive or will receive services under programs modified as a result of states' increased flexibility under the Administration's HIFA waiver policy, and possibly under the President's proposed Medicaid reforms.

- First, states' experiences under SCHIP indicate that states will take advantage of the flexibility offered by the Administration's policy to scale back benefit packages and impose premiums and cost-sharing to make their public programs "look more like private insurance." This is not necessarily an issue for all individuals since most people are healthy and essentially require maintenance care, but it can be for individuals who have special needs that require services in amounts that exceed the norm.

- Second, states' experiences in addressing the needs of CSHCN under SCHIP indicate that the majority of states have not focused their attention on individuals who may require services beyond those covered in the scaled back benefit packages, with only a handful having designed special programs to address the needs of such individuals.

- Third, in states with special programs for CSHCN, individuals with certain health problems, such as behavioral conditions, still run the risk of lacking access to appropriate behavioral health care, unless there is an organized referral system to other state programs that furnish behavioral services.

- Finally, even in states with an organized referral system to behavioral programs, individuals with behavioral conditions for whom it is the only diagnosis may not qualify for these mental health and substance abuse programs because their condition may not meet the severity criteria used by the programs as a condition of eligibility or because the programs may impose a cap on enrollment. These individuals would thus face the limitations of the SCHIP benefit package with nowhere else to turn for needed specialty care.

As an increasing number of states take advantage of a renewed flexibility under HIFA to re-design their Medicaid and SCHIP programs, this study suggests that states may want to pay particular attention to children and adults with special needs. Mobilizing the multiple state agencies whose mission is to serve such individuals at the design stage to create a system where these individuals can be directed to the appropriate sources of care, and coordinating the delivery of services at the implementation stage are two important lessons drawn from this research that will help ensure that fewer CSHCN and other individuals with special needs will fall through the cracks and more of them will receive services that will fill in the gaps left by the scaled back benefit packages under reengineered public health insurance programs.

INTRODUCTION

The State Children's Health Insurance Program (SCHIP) permits states to extend health insurance to uninsured "targeted low income" children who qualify for aid based on a state's financial eligibility criteria[1] and who are otherwise ineligible for "creditable health coverage," as defined under federal law.[2] As of the end of 2001, all states and the District of Columbia participated in SCHIP; of these, 15 states and the District of Columbia operated their programs as Medicaid expansions only, while the remaining 35 states elected to administer SCHIP as a separate program in whole or in part. States that elect to separately administer SCHIP must meet certain minimum requirements regarding eligibility, benefits and cost-sharing, but the requirements are more relaxed than those that apply to Medicaid, particularly with respect to the scope and depth of coverage that must be provided, the medical necessity standard that must be used, and the use of premiums, deductibles and copayments.[3]

Previous research into the design of separately-administered SCHIP programs suggests that states use their flexibility to design programs that more closely approximate the type of "major medical" health insurance coverage available through employer-sponsored benefit plans. Indeed, a major goal of SCHIP was to provide states with necessary resources to assist near-poor families with uninsured children secure health insurance without requiring states to adopt programs that provide the extent, depth, and scope of coverage to which Medicaid-enrolled children under age 21 are entitled under the Medicaid Early and Periodic Screening Diagnosis and Treatment (EPSDT) program. Benefit design studies that examine separately-administered SCHIP programs confirm that separately-administered SCHIP programs tend to cover a range of benefits somewhat less broad than that available through Medicaid (particularly with respect to long term care services) and employ coverage limits (such as limits on the number of visits for services to treat mental illness or developmental disabilities) that would not be permissible under Medicaid.[4] Furthermore, only six states with separate programs incorporate into their programs the pediatric medical necessity standard that characterizes the EPSDT program. This special standard of medical necessity, which is one of the fundamental hallmarks of Medicaid that distinguishes the program from conventional health insurance, requires coverage far beyond situations in which care may be medically necessary to allow a child to recover (or significantly improve) from an illness or injury.[5] Under the Medicaid EPSDT program, coverage also must be provided when the care is necessary to prevent the deterioration of a condition or help the development and functioning of children with long term chronic physical, mental, or developmental conditions from which "recovery" or "significant improvement" (as the terms are use in conventional insurance plans) may not be possible.[6]

In states that elect to administer SCHIP as a separate program and that choose to design their programs to more closely parallel the types of benefits and coverage rules found in employer-sponsored plans, an important question becomes the extent to which states supplement their SCHIP plans with additional or complementary services in the case of children with special health care needs (CSHCN), i.e., children whose physical, developmental or mental health conditions create at least a potential need for services and treatments that go beyond conventional insurance norms. One possible source of supplemental or complementary services for such children is the Title V Maternal and Child Health Services Block Grant program.

This Issue Paper examines states' use of Title V to complement their SCHIP programs in the case of special needs children. The approaches that states use in supporting children who are enrolled in separate SCHIP programs and who thus are not entitled to the full range of Medicaid benefits is of particular importance given the high degree of current interest, as evidenced by the Administration's Health Insurance Flexibility and Accountability (HIFA) demonstration initiative and the President's proposed Medicaid reforms, in the issue of Medicaid benefit design flexibility. What approaches do states take in supporting SCHIP-enrolled CSHCN and their families? Specifically, what is the role played by state Title V programs, whose historic roots lay in great part in the provision of services to children with long term physical disabilities? What lessons can be learned for the coverage of children and adults with disabilities?

The study that is the subject of this Issue Paper has three purposes:

(1) to describe the Title V Maternal and Child Health Services Block Grant program as it pertains to children with special health care needs (Title V CSHCN programs);

(2) to explore the level of interaction and coordination between Title V CSHCN programs and separate SCHIP programs in terms of providing services to children with special health care needs; and

(3) to assess the implications of state program choices for publicly-funded health insurance programs and pediatric health care.

The Issue Paper begins with a background and overview of the Title V Maternal and Child Health Services Block Grant program and presents data on the characteristics of Title V programs as they pertain to CSHCN. The second section presents the study's principal findings, including the three basic models developed by states with separate SCHIP programs to address the health care needs of CSHCN, and the final section discusses the implications of these findings for publicly-financed health insurance programs and pediatric health care.

THE TITLE V MATERNAL AND CHILD HEALTH SERVICES BLOCK GRANT PROGRAM

Purpose, History and Evolution: Title V is one of the nation's oldest health programs and represents a pivotal part of the beginning of the modern maternal and child health policy era.[7] Enacted in 1935 as part of the original Social Security Act and codified at Title V, the legislation represented one of the very first state "grant-in-aid" programs, allocating federal revenues to states that agreed to meet the program's basic conditions of participation. The original program involved the allotment of $2.7 million to states in FY 1936; by FY 2002, the federal allotment had grown to not quite $732 million.

The original Title V programs reflected two basic Congressional goals. The first was to assist states lessen the negative social and public health impact of the Great Depression through promotion of maternal and child health services and the development of a basic preventive and primary health care infrastructure for women and children. The second, and one directly tied to the terrible epidemic of poliomyelitis, was to assist states through grants to develop services for "crippled children."

Following its enactment, Title V was broadly implemented by states that sought to provide programs for maternity, infant and primary pediatric health care, as well as medical and "after-care" services (i.e., rehabilitation) for "crippled children," including children with crippling illnesses such as polio and congenital disabilities.[8] By 1938, all but one state had established a "Crippled Children's" program; programs were designed to address these children's social and emotional needs as well as their physical care.[9] During the 1950s, Congress added special funding to support the development of projects targeting "mentally retarded" children.[10] The 1960s witnessed additional funding to develop "special projects" of maternity and infant care, primary care for children and youth, and special federally conducted projects of regional and national significance for children with specialized health problems such as hemophilia.[11]

In 1981, as part of the Omnibus Budget Reconciliation Act, Title V was consolidated with seven smaller categorical programs under what is known today as the Title V Maternal and Child Health Services Block Grant.[12] This consolidation was designed to give states considerably more flexibility and discretion in setting their own priorities; among other changes, the consolidation eliminated the maternity and infant care and children and youth projects and gave states greater latitude to set service priorities.[13]

Both the special needs and primary care-related purposes of Title V have been restated and expanded over the years, as the focus of child health has shifted over time and as social mores and attitudes and beliefs have changed. Of particular relevance to this study was the shift from "crippled children" to the concept of "children with special health care needs" through Congressional amendment in 1985. The term "children with special health care needs," as used by the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration, in implementing the statute, is as follows: "children under 21 who have a chronic physical, developmental, or behavioral condition, and require health and related services of a type or amount beyond that which is required by children generally."[14]

Congress amended the program in 1989 to increase state application and reporting requirements, expand the program's role in the delivery of rehabilitation services for disabled children under age 16 not covered by Medicaid, and provide and promote family-centered, community-based coordinated care, including care coordination services. Amendments in 1996 added abstinence training to the program's overall goals.

Table 1. Title V Legislative Milestones

Date	Legislative Milestones
1912	Children's Bureau created by Congress, placed in Department of Commerce and Labor
1935	Title V legislation enacted as part of SSA and administered by Children's Bureau
1943	Emergency Maternity and Infant Care Program enacted (P.L.78-156)
1954	Mental Retardation becomes a Title V program priority
1963	Maternal and Child Health and Mental Retardation (MR) Planning amendments (MR Programs, Maternal and Infant Care Projects, Research Program) enacted
1965	SSA amendments (Children and Youth Projects, Training Program, Dental Projects) enacted
1967	SSA amendments (Family Planning Services and Projects, Intensive Newborn Projects) enacted
1969	Title V transferred to Public Health Service
1976	SSI Program for Children enacted
1981	OBRA '81 MCH Services Block Grant
1984	Emergency Medical Services for Children Act enacted
1988	Pediatric AIDS Projects developed in Title V set-aside
1989	SSA amendments (accountability of State programs increased)
1990	Maternal and Child Health Bureau (MCHB) established to administer Title V
1991	Healthy Start enacted
1997	SSA amendments (Abstinence Education Program) enacted
1998	Title V Information System established by MCHB

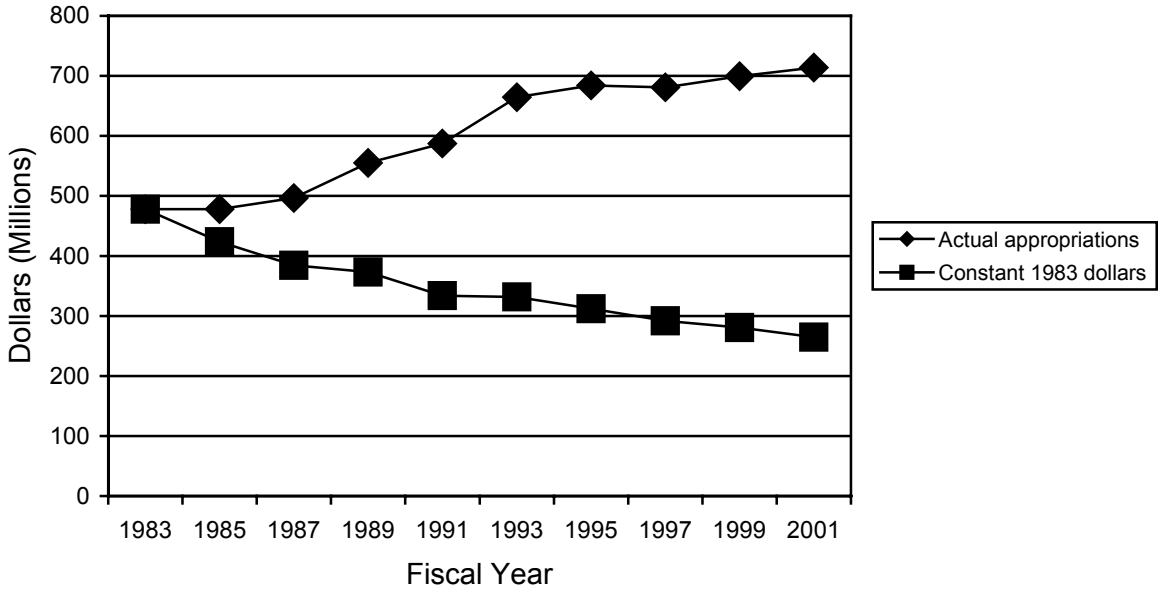
Source: MCHB, HRSA, DHHS.

In sum, this overview of Title V shows that despite its relatively modest size, Title V has been revisited by Congress repeatedly over the years as new maternal and child health related concerns become evident. Even with the enactment of Medicaid in 1965, the EPSDT program in 1967 (which simultaneously amended Medicaid and Title V to increase support for primary care) and SCHIP in 1997, Title V has continued as a source of flexible funding that allows states to invest in the child health "infrastructure" for both basic care and special needs purposes. At the same time, the fact that a series of public health financing programs simultaneously are focusing on low-income and special needs children raises important issues of coordination. Toward this end, the federal Title V and Medicaid statutes specifically require state Title V and Medicaid agencies, as a condition of federal funding, to coordinate their activities. And while the SCHIP statute requires states to describe the procedures they will use to coordinate their SCHIP program with Title V programs, the Title V statute contains no coordination requirements between Title V and SCHIP similar to those imposed on Title V and Medicaid.

Program structure: Title V is a federal-state partnership. It is a permanently authorized discretionary federal grant program, for which $850 million are currently authorized. Different rules apply depending on the actual level of appropriations made for the program. When appropriations are below $600 million, 85 percent of the funds must finance block grants to states who apply for service delivery and infrastructure funds, with the remaining 15 percent set aside at the federal level for "Special Projects of Regional And National Significance" (known as the SPRANS program), which include projects relating to maternal and child health research, genetic disease testing and counseling, and traumatic brain-injury services.[15] When

appropriations exceed $600 million, a second set-aside of 12.75 percent of the funds goes to Community Integrated Service Systems (CISS), such as home visiting programs and projects for CSHCN. In FY 2002, $732 million were appropriated to the program, compared to $714 million in FY 2001 and $709 million in FY 2000.[16] Since the early 1990's, federal funding in nominal terms has remained relatively flat; adjusted for 1983 dollars, appropriations have actually declined over time (Figure 1).[17]

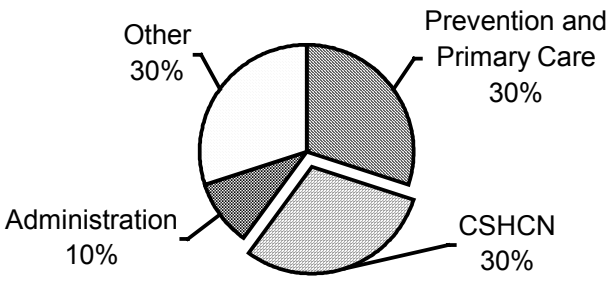
Figure 1. Title V Annual Funding Levels over Time, FY 1983- FY 2001



Source: AMCHP, 2002.

States are required to spend three dollars for every four federal dollars in federal Title V allotments. In addition, federal law establishes certain broad proportional expenditure targets. States must spend 30 percent of funds on prevention and primary care for children and adolescents, 30 percent of funds on CSHCN, 10 percent of funds on administration of the program; undergo a comprehensive statewide needs assessment and planning; maintain state FY 1989 funding levels; and coordinate with Medicaid, SSI, WIC, family planning, education, developmental disability, and other related programs. States must annually report on national and state-specific performance measures.[18]

Figure 2. State spending requirements under Title V



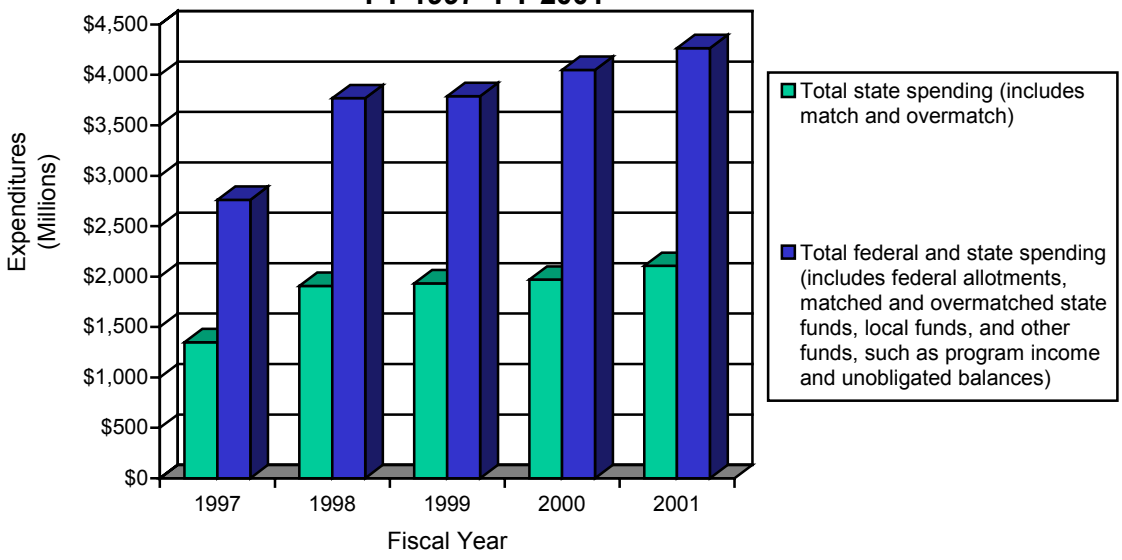
Source: MCHB, HRSA, DHHS, 2002.

Since 1981, states have enjoyed more leeway in determining how to use federal funds based on identified state and local maternal and child health needs. State activities under Title V span the spectrum and include the following objectives:

- To monitor health problems and identify service gaps and barriers to target resources
- To set and monitor standards and provide training and technical assistance
- To integrate health services with other child and family services (e.g., child care, Head Start, school health, child protective services)
- To support community- based networks of preventive and primary care
- To assist families in identifying and appropriately using resources through outreach and case management, health education, referral, transportation, and nutrition counseling
- To assist families whose children have chronic illnesses and disabilities in obtaining a complex array of needed services at the community level.

The total cost of these various activities was approximately $4.2 billion in combined federal and state spending for FY 2001 (Figure 3).

Figure 3. Federal and state spending under Title V, FY 1997- FY 2001



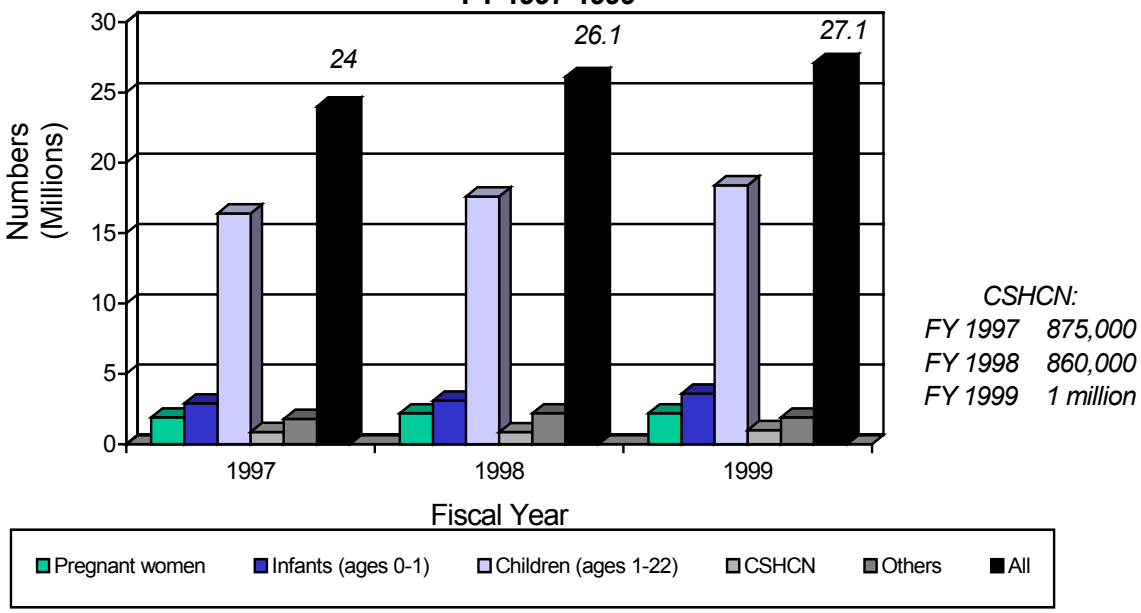
Source: Title V Information System, MCHB, HRSA, DHHS at www.mchdata.net, 2003.

Population served: Title V has a broad mission of promoting and improving the health of all mothers and children. In addition, programs funded through Title V are often the health safety net for women and children who lack access to care. In FY 1999, over 27 million women and children, received care through these programs (Figure 4). This represents an increase of 3 million over the number of people served in 1997.

While the basic mission of the program is quite broad—promotion and improvement of maternal and child health nationwide—the Title V legislation also contains a number of specific purposes for which states may apply for funding, one of which strictly relates to CSHCN. Under Title V, funds can be used to provide and promote family-centered, community-based coordinated care systems for CSHCN and their families.[19] As a result, Title V programs provide specialized health and family support services to thousands of children with chronic conditions and disabilities. In FY 1999, one million CSHCN were served by these programs (Figure 4)—approximately one half of the nation's children with severe disabilities and 20 percent of those

with chronic conditions.[20] The number of CSHCN who received services from Title V programs grew 12 percent over the FY 1997 to FY 1999 period.

Figure 4. Population served by Title V programs, FY 1997-1999



Source: Title V Information System, MCHB, HRSA, DHHS at www.mchdata.net, 2002.

Services provided: State Title V agencies deliver a number of core public health services that fall into four main levels of care, according to MCHB typology.

The first level of care, Level I, consists of direct health care services that are gap filling. Examples of such services are basic health services and services for CSHCN, which include medical and surgical subspecialty services, occupational and physical therapy, speech, hearing and language services, respiratory services, durable medical equipment and supplies, home health care, nutrition services, care coordination and early intervention services.

Level II consists of enabling services, such as transportation, translation, outreach, respite care, health education, family support services, purchase of health insurance, case management, coordination with Medicaid, WIC and education programs.

Population-based services make up Level III and encompass newborn screening, lead screening, immunization, SIDS counseling, oral health, injury prevention, nutrition, outreach and public education, among other services.

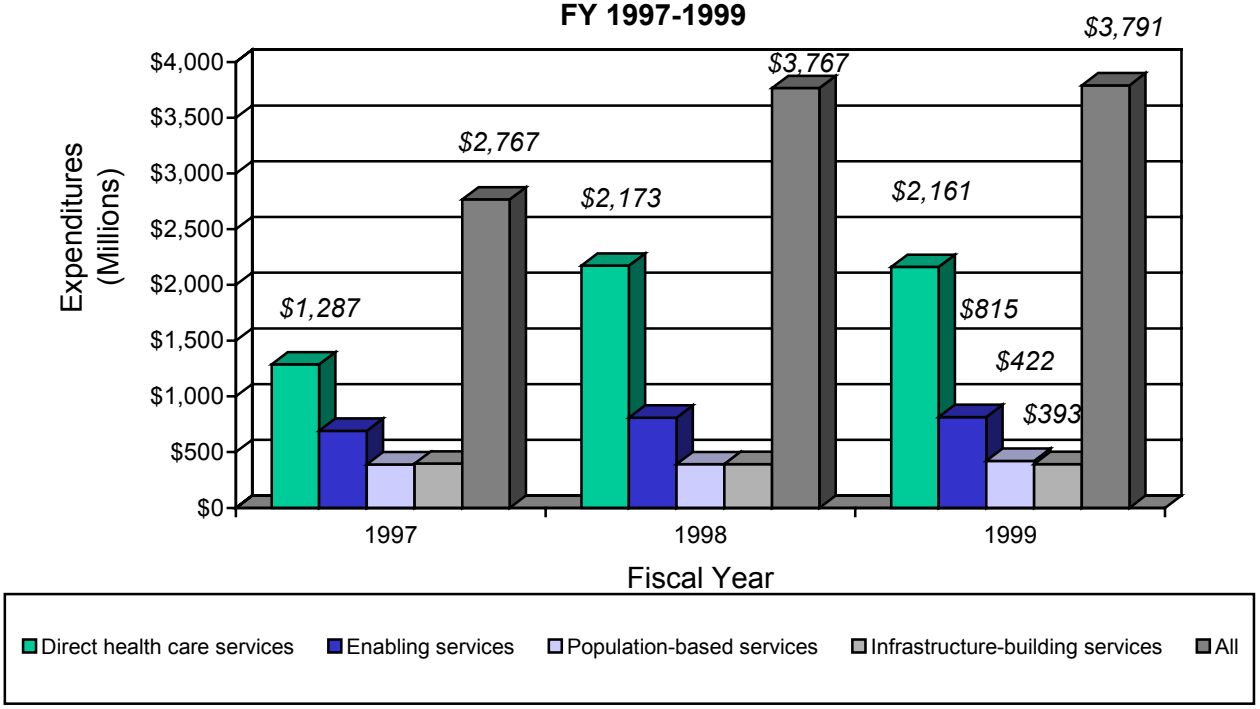
The final level of care, Level IV, is composed of infrastructure building services, e.g., needs assessment, evaluation, planning, policy development, coordination, quality assurance, standards development, monitoring, training, applied research, systems of care, and information systems.

Depending on its state and local needs, a state will invest in a certain mix of services that can be quite different from other states. For example, spending on enabling services

ranges from .3 percent in Ohio to 60.9 percent in Alaska.[21] States' total expenditures will also vary from state to state.

In the aggregate, direct health care services are by far the largest spending item, with over 50 percent of the funds invested in such services. Figure 5 shows that, in FY 1999, states spent 57 percent on direct health care services, 22 percent on enabling services, 11 percent on population-based services, and 10 percent on infrastructure-building services. However, as with other categories of services, states demonstrate enormous variations in the investment they make in direct services. For example, expenditures on direct services range from a low .2 in Connecticut to a high 91.1 percent in Ohio.[22] State investment in direct health care services is a function of many factors, including the comprehensiveness of the Medicaid and SCHIP benefit package offered by the state, the percentage of uninsured women and children in the state, and the perceived need for providing services excluded from the Medicaid and SCHIP programs.[23] Figure 5 shows that spending for direct health care services grew significantly between FY 1997 and FY 1998, perhaps as a reaction to a number of factors, including an increase in the total population served due in part to the establishment of the SCHIP program in many states and a decrease in the number of Medicaid-covered children, the start-up of the abstinence education program, and the implementation of the Title V information system.

Figure 5. Title V spending by type of service, FY 1997-1999



Source: Title V Information System, MCHB, HRSA, DHHS at www.mchdata.net, 2002.

Relationship with Medicaid and SCHIP: In this discussion about coordination between Title V and SCHIP, it is important to consider how the Title V program relates to the Medicaid and SCHIP programs. All three programs are codified in the Social Security Act, as Title V, Title XIX (Medicaid), and Title XXI (SCHIP). All three programs are federal and state matching programs. However, Medicaid is an open-ended federal entitlement to states and an individual entitlement to eligible low-income children; SCHIP is a capped federal entitlement to states; and Title V is a discretionary federal grant program, which is appropriated each year.

The structure of the programs reflects different, but not necessarily opposing philosophies about the provision of health care to children. Medicaid and SCHIP are targeted at low-income children only; Title V is for all children, although it does act as a safety net for low-income children. The primary role of Medicaid and SCHIP is as a health insurer; Title V is a broad and flexible source of federal funds for states to develop and support a wide range of primary and specialty care services. Finally, the federal and state agencies responsible for administering the programs belong to different departmental divisions: Medicaid is administered by the Centers for Medicare and Medicaid Services (CMS) at the federal level and Medicaid agencies at the state level; SCHIP is administered by CMS and MCHB at the federal level and SCHIP agencies (which can be the same agency as the state Medicaid agency) at the state level; and Title V is administered by MCHB at the federal level and Title V agencies at the state level.

MODELS OF COORDINATION BETWEEN SCHIP AND TITLE V

Study Structure

Because coordination among state programs is important to ensure that CSHCN have access to services beyond those offered under separately-administered SCHIP programs, the starting point for this research is the broad requirement contained in the SCHIP statute that states electing to participate in SCHIP coordinate the administration of their program with other public and private health insurance programs.[24] The SCHIP implementing rules further specify that the state plans must describe the "procedures the State uses to accomplish coordination of SCHIP with other public and private health insurance programs, sources of health benefits coverage for children, and relevant child health programs, such as title V, that provide health care services for low-income children."[25] This language makes it clear that, even though Title V is not a public health insurance program, it is an important source of financing for services for SCHIP-covered children that requires some linkage to the SCHIP program.

Table 2. Coordination Requirements under Federal Law

Title V	Title XIX	Title XXI
■ Requires state Title V agencies to enter into interagency agreements with Medicaid agencies (e.g., participation in Medicaid, reimbursement of Medicaid-covered services delivered to Medicaid beneficiaries) ■ Requires state Title V agencies to coordinate activities between the state Title V program and Medicaid (e.g., EPSDT benefit, outreach and enrollment assistance) ■ Does not impose similar requirements regarding SCHIP	■ Requires state Medicaid agencies to enter into interagency agreements with Title V agencies (e.g., participation in Medicaid, reimbursement of Medicaid-covered services delivered to Medicaid beneficiaries) ■ Does not require state SCHIP programs to coordinate with Title V agencies	■ Requires states to describe and assess the procedures they will use to coordinate their SCHIP program with other public and private health insurance programs, sources of health benefits coverage for children, and relevant child health programs, such as Title V, that provide health care services for low-income children ■ Requires states to screen children for Medicaid eligibility first and enroll them in Medicaid if found eligible for the program

Source: CHSRP, 2002.

In the context of the SCHIP program and CSHCN, state Title V agencies have the option to choose from three basic coordination strategies, alone or combined, in order to coordinate the administration of SCHIP and Title V to enhance services for CSHCN:

1) use their expertise on CSHCN to advise the SCHIP program on the purchase of services for CSHCN;

2) lead outreach activities to CSHCN eligible for SCHIP to assist them in enrolling in the program and to initiate the provision of services until the child is enrolled; and

3) provide services not covered by the SCHIP program.[26]

This study focuses on the last approach. We were particularly interested in states that had made the deliberate policy choice of integrating, in some organized fashion, their Title V CSHCN program into their SCHIP program at the time of program design. We were also curious to learn whether Title V agencies in those states had made any changes to their programs as a result of the implementation of SCHIP. To that end, we reviewed existing research findings on states' early experience with implementing the program, which together covered a majority of separately-administered SCHIP programs (51%) and SCHIP enrollees (74%), analyzed the coordination and benefit provisions of the 35 state separate SCHIP plans filed with CMS as of December 2000, surveyed in writing in 2001 Title V agencies in the 35 states with separately-administered SCHIP programs regarding changes to their CSHCN program after SCHIP was enacted, and created comparative tables of a core set of benefits frequently needed by CSHCN based on information compiled from the state SCHIP plans and the 2000 Edition of the "Directory of State Title V CSHCN Programs-Eligibility Criteria and Scope of Services" and validated by Title V agencies (response rate=51%).[27]

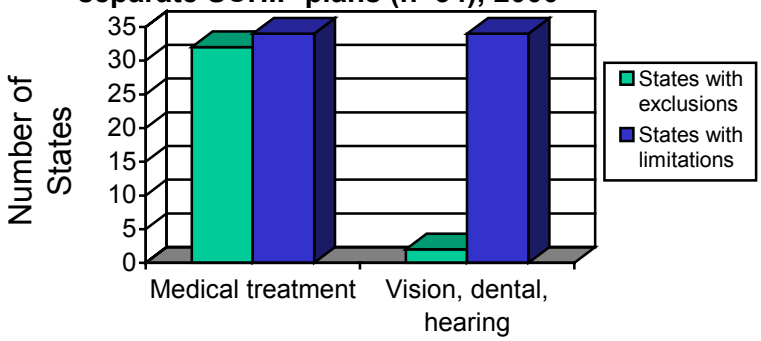
Study Results

This section is divided into two main parts. In the first part, we delineate models of integration of SCHIP with Title V CSHCN programs, based on the experiences of six states that made CSHCN a priority in the design phase of their separate SCHIP programs. The second part summarizes findings from state-by-state profiles, which provide synopses of the relationship between the two programs in each state and data comparing enrollment, eligibility, and services covered under each program. The profiles are in the Appendix attached to this report.

Program Design Phase: Models of Coordination between SCHIP and Title V

Previous research by the Center for Health Services Research and Policy (CHSRP) and by others has found that separately-administered SCHIP programs typically offer benefits that are more limited than those in Medicaid (Figure 6).[28] They also tend to exclude or place limits on services that can be critical to CSHCN. Services such as nonemergency transportation, care coordination, respiratory care, and personal care services tend to be excluded altogether, while

Figure 6. Benefit exclusions and limitations in separate SCHIP plans (n=34), 2000



Source: CHSRP, 2001.

services, such as physical, occupational and speech therapy, rehabilitation care, prescription drugs, vision, dental, and hearing care, hospice care, mental health and substance abuse services, and durable medical equipment, face serious limitations in scope, duration and amount. The prevalence of limitations and exclusions in benefit packages offered by separately-administered programs raises the question of whether these programs have the ability to appropriately meet the needs of CSHCN, unless they have made the deliberate policy decision to address those needs when designing the program.

According to recent research on the early implementation efforts of state SCHIP programs, "CSHCN were 'not even on the radar screen,' as policymakers focused on the broader issue of how best to extend health insurance to children in general."[29] This research further found that only a handful of states had considered CSHCN during program design and included Title V agencies responsible for this population in their discussions about what the program should look like.[30] Based on this research, we have delineated three basic models of addressing the needs of CSHCN in the SCHIP context: (1) the "service supplement" model; (2) the "specialty care carve-out" model; and (3) the "person carve-out" model.

Model 1: The "service supplement" model. The state offers a basic benefit package resembling commercial insurance in its SCHIP program and supplements those basic benefits with "wrap-around" services that go beyond the scope, amount or duration of the SCHIP benefits. Three states—Alabama, Connecticut, and North Carolina—fall into this category. They opted for commercial-like benefit packages for their SCHIP program (the state employee benefit package in Connecticut and North Carolina; the benefit package offered by the HMO with the largest commercially-insured enrollment in Alabama) precisely because of the appeal of these packages as commercial insurance. At the same time, these states recognized that the SCHIP benefit package might not provide sufficient coverage for CSHCN. As a result, these three states decided to supplement the basic SCHIP package with wrap-around coverage of a set of enhanced benefits (e.g., the basic SCHIP package may limit the number of home health care visits and the state's Title V CSHCN agency will cover additional visits to the extent that funds are available). In addition, Alabama designed a new service delivery arrangement to respond to the needs of CSHCN, under which participating agencies that have traditionally served CSHCN in the state (which include the state Title V CSHCN agency) provide the SCHIP state match for the extra services needed subject to the service and funding capacity of these agencies.

In the second and third models, states, including California, Florida, and Michigan, decided to incorporate special CSHCN initiatives that existed prior to SCHIP so that SCHIP-covered children would have the same opportunity to receive specialized services as Medicaid-covered children. Two distinct models emerge, however.

Model 2: The "specialty care carve-out" model. The state completely excludes certain specialty care services in its SCHIP program and has an existing specialty care carve-out program for CHSCN, which is incorporated into SCHIP. In this model, the SCHIP program completely excludes certain specialty care services, such as private duty nursing, and refers SCHIP-eligible children in need of those services to the Title V CHSCN program, which covers that service to the extent that funds are available. California falls into this category. The California Children's Services program is a broad network of primary, specialty and ancillary providers serving children eligible for the Title V CSHCN program, which administers a specialty care carve-out program for children eligible for the Title V CSHCN program who are enrolled in Medi-Cal (Medi-Cal plans are in effect lifted from the duty of furnishing specialty care). This

arrangement was extended to Title V eligible children enrolled in Healthy Families, the state's separate SCHIP program.

Model 3: The "person carve-out" model. The state refers SCHIP-eligible CSHCN to a special, Title V administered managed care system or other integrated health care delivery system for CSHCN, which is incorporated into SCHIP. In this model, SCHIP-eligible CSHCN are referred to a special system of care administered by the Title V CSHCN agency, which provides the full spectrum of services. Florida and Michigan fall into this category; both states had a special managed care system in place prior to SCHIP. Florida's Children's Medical Services Network was incorporated into KidCare as one of the service delivery options for CSHCN enrolled in SCHIP. Michigan's Special Health Plan, which had been made available to Medicaid-covered CSHCN since 1998, was extended to SCHIP-covered CSHCN under MIChild.

Overall, the six states identified above stand out for their concerted efforts to address the needs of CSHCN.[31] In comparison, the majority of states with separately-administered SCHIP programs have been less active in their efforts to serve CSHCN and coordinate with Title V CSHCN programs. In these states, SCHIP programs appear to rely heavily on the state's existing Medicaid medically needy program. In fact, preliminary results from case studies conducted by CHSRP in five states indicate that at least two of these states assumed that CSHCN, if SSI eligible (other than for their family income level), would enroll in Medicaid through the medically needy program. Further research would be needed to determine whether that link actually materializes or whether children fall through the cracks instead. A previous study by CHSRP found that, although the majority of states with separate SCHIP programs also have a Medicaid medically needy spend-down program in place, families' spend-down obligations would be quite large, even for families with children who have higher than average health needs, prompting the conclusion that the alternative coverage route of Medicaid following a large spend-down would be far less desirable than being able to take advantage of immediate coverage through SCHIP.[32] In addition, the definition of disability under SSI is quite strict, in effect excluding many children who are not severely disabled, yet require amounts of services beyond that usually needed by children the same age.

Program Implementation Phase: Improvements and Gaps in Coverage

All six states were included in this study precisely because of their explicit efforts to coordinate their SCHIP and Title V programs to better serve CSHCN. Our state Title V contacts described the design of their separate SCHIP program as an endeavor in which the two state agencies responsible for these programs "worked together" (Alabama), "worked in tandem" (Connecticut), or "forged a partnership" (North Carolina). They also described a collaboration that continued well into the implementation of the SCHIP program. Changes to the Title V CSHCN programs occurred in the majority of these states following the implementation of the SCHIP program, but the type of change undertaken varied from state to state. Two states, Alabama and California, expanded coverage for certain services such as enabling transportation and vision care. Connecticut transferred all of its Title V enrollees to HUSKY Part B, the state's separate SCHIP program, and started focusing on underinsurance. Finally, North Carolina's Title V agency became responsible for coordinating the additional benefits provided to CSHCN and monitoring the quality of care furnished. In addition to these improvements in coverage, findings regarding enrollment and expenditures, eligibility, and services also suggest potential gaps, particularly in the coverage of some services, even in these states, unless other sources of care are available to fill in those gaps.

***Enrollment and expenditures*:** Together, the six states included in this study represent 25 percent of the estimated 10.6 million children who have special needs nationwide.[33] Although data on the actual number of CSHCN enrolled in separate SCHIP programs are not widely available, study states' estimates indicate they expected a sizable portion of these children to enroll in their separate programs. These estimates range from a low 1 percent of SCHIP-eligible children in California to a high estimate of 9 percent in Alabama. In contrast, Title V agencies do record this information since one of their specific missions is to serve CSHCN. The number of CSHCN served varies from a low 5,284 in Connecticut to a high 133,007 in California.[34] Similarly, while data on expenditures incurred for services provided to CSHCN are lacking in separate SCHIP programs, such data are available for Title V services. In this case, estimates range from $11.9 million in Connecticut to $1.1 billion in California.[35]

***Eligibility*:** Under SCHIP law, states may base eligibility for their separate SCHIP program on disability status as long as their standards relating to disability status do not restrict eligibility. In all six states, as is the case for the remaining states with separate SCHIP programs, children are eligible for the separate SCHIP program regardless of disability. However, the majority of these states (Alabama, California, Connecticut and Florida) specify that SCHIP-covered children must meet the eligibility criteria of the Title V CSHCN program to obtain services, whether it is through the "service supplement" model (Alabama, Connecticut), the "specialty care carve-out" model (California), or the "person carve-out" model (Florida).

Title V CSHCN programs usually have age, income, and condition-based eligibility standards. They also subject eligibility to the service and funding capacity of the program. This means that, despite the availability of Title V programs, some SCHIP-eligible children will not be able to receive services under these programs, if, for example, their medical condition is not on the list of Title V covered conditions (e.g., mental disorders, mental retardation), the service they need is not reimbursed by Title V (e.g., orthodontia, outpatient mental health services), or the agency runs out of funds. These children could still be eligible, however, for other programs offered through other state agencies, such as state mental health departments, when available.

- *Age:* The majority of the study states cover children ages 0-21 (California, Florida, Michigan, North Carolina), while two states (Alabama, Connecticut) cover children ages 0-19. The majority of these states also have exceptions for hemopheliacs and individuals with cystic fibrosis, for whom there is no age limit.

- *Income:* The majority of the study states ask that children who are eligible for Title V services and who are also eligible for public coverage through Medicaid or SCHIP use these insurance programs, which function as their primary payor of care. Other children who have special needs but do not qualify for either program receive services through Title V, and children above a certain income level may be asked to participate financially in their care.

- *Condition:* All state Title V CSHCN programs have a definition of medical eligibility, but only two states (Connecticut, Florida) use the MCHB definition, which is based on service use beyond that of typically healthy children, to determine whether a child has a special health care need. In contrast, only half of the state SCHIP plans (Alabama, Connecticut, and North Carolina) provide a definition of what the program considers CSHCN, but as is the case with Title V, only two states (Alabama, Connecticut) use the MCHB definition. This means that the majority of the Title V CSHCN programs in this study determine medical eligibility for their services mostly on the basis of a list of covered conditions or diagnoses to determine eligibility for

their services. They may also explicitly exclude certain conditions, e.g., mental disorders and mental retardation, when they are the only diagnosis.

***Services*:** Because of the nature of the SCHIP and Title V programs—neither are open-ended entitlements like Medicaid—SCHIP and Title V CSHCN agencies make eligibility for their programs subject to the availability of services within the Title V CSHCN program and to the availability of resources within both agencies. In fact, Alabama and Connecticut are two states that explicitly condition specialized physical services for CSHCN upon availability of services and resources. A side-by-side comparison of services covered by SCHIP and Title V in the study states suggests that three categories of services that are critical to CSHCN may lack sufficient coverage—oral health, mental health and substance abuse, and enabling transportation—even with the high level of coordination that exists between SCHIP and Title V in these states, unless there is a good referral system to other sources of care that can provide these services (Table 3).

- *Oral health services*: All of the study states' separate SCHIP programs cover dental care, but the majority imposes limitations on its scope, duration, and amount. Similarly, the majority of Title V CSHCN programs provide dental services with limitations, with one additional state excluding this category of benefit altogether.

- *Mental health and substance abuse services*: The majority of SCHIP programs limit coverage of mental health and substance abuse services, particularly those provided on an outpatient basis. Because of the traditional emphasis of Title V on physical services, Title V CSHCN programs would not be expected to provide the full spectrum of behavioral services, especially since other agencies in the state are usually responsible for these services. On the other hand, because of the enactment of SCHIP and its somewhat limited coverage of behavioral health services, Title V agencies could presumably have made some adjustments for CSHCN enrolled in SCHIP who would need such services. As this research shows, however, the majority of Title V agencies exclude coverage for inpatient and outpatient mental health services, and all agencies exclude coverage for inpatient and outpatient substance abuse services. More than half of the states explained why this was the case. In North Carolina, another agency in the state covers these services. In California, Connecticut and Florida, SCHIP-covered CSHCN in need of such services are referred to other sources of care, i.e., the behavioral specialty care system run by the county mental health departments in California, HUSKY Plus Behavioral in Connecticut (the SCHIP supplemental insurance program specifically created for specialized behavioral services), and the network of providers overseen by the Department of Children and Families under an agreement between the Department and Children's Medical Services (the state Title V agency) in Florida.

- *Enabling transportation services*: The majority of separate SCHIP programs exclude coverage of enabling transportation. In comparison, Title V CSHCN programs exclude it altogether (3 states) or cover it with limitations (2 states). Although an exception among the study states, the California Title V agency, for example, reported that it provides some services such as transportation above those offered by the SCHIP plan related to the Title V eligible conditions. In effect, in this state where the state SCHIP plan excludes coverage of enabling transportation, the Title V CSHCN program filled in the gap for CSHCN who are covered under SCHIP and eligible for Title V services, as a direct consequence of the implementation of SCHIP.

Table 3. Comparison of the Extent of Coverage of a Core Set of Services Frequently Needed by CSHCN under Separate SCHIP and Title V CSHCN Programs (N=6)

	SEPARATE SCHIP PROGRAM			TITLE V CSHCN PROGRAM		
	Covered	Covered with limitations	Excluded	Covered	Covered with limitations	Excluded
Lab and x-ray	6			5		1
Vision care	4	2		2	1	3
Hearing care	4	2		4	1	1
Home health services	3	3		2	2	2
Dental services	2	4		1	4	1
Physical therapy, occupational therapy, Speech therapy	5	1		3	1	2
Prescriptions	4	2		5		1
Medical supplies	4	2		4	1	1
Durable medical equipment	4	2		5		1
Inpatient mental health services	3	3			1	5
Outpatient mental health services	2	4			1	5
Inpatient substance abuse services	4	2				6
Outpatient substance abuse services	2	4				6
Case management	3	1	2	3	1	2
Care coordination	3	1	2	5	1	
Medical transportation	4	2		2	1	3
Enabling transportation	2		4	1	2	3

Source: CHSRP, 2002.

DISCUSSION AND CONCLUSION

This study described the Title V Maternal and Child Health Services Block Grant program, including Title V CSHCN programs, and explored the level of interaction and coordination between Title V CSHCN programs and separate SCHIP programs in the provision of services to children with special health care needs.

Overall, our findings show that the majority of states with separate SCHIP programs have not taken explicit steps to ensure that their programs interact with the state Title V CSHCN program and coordinate services for CSHCN. Rather, it appears, as preliminary research conducted by CHSRP seems to indicate, that these states have opted to rely on their Medicaid medically needy program as a way to direct CSHCN to the comprehensive benefits offered by the Medicaid program.

On the other hand, our findings also show that some states have in fact specifically addressed the needs of CSHCN during the design phase of their separate SCHIP program. These state program design choices fall under three basic approaches to SCHIP and Title V integration we delineated based on prior research conducted by CHSRP and others: the "service supplement" model; the "specialty care carve-out" model; and the "person carve-out" model. All three approaches may serve as models for other states that wish to coordinate services with Title V agencies and have not yet done so. Of the three models, the first one may be the most feasible, especially for states that do not have a special Title V program already in place, as was the case in Florida and Michigan.

In addition to making clear program design choices targeted at CSHCN, the majority of the study states reported having made changes to their Title V CSHCN programs following the implementation of SCHIP, from expanding coverage of certain physical and enabling services to becoming the coordinating agency for the additional benefits provided to SCHIP-covered CSHCN. They also reported a continuation of the collaboration that had started in the design phase into the implementation phase.

By pursuing collaboration in both the design and implementation phases of separate SCHIP programs, SCHIP and Title V CSHCN agencies can increase the likelihood that CSHCN enrolled in SCHIP will receive needed care beyond what would be available through the basic SCHIP program. However, several lingering issues remain based on the findings of this study.

First, SCHIP-covered CSHCN must meet Title V eligibility criteria in order to receive the services reimbursed by the Title V agency. While the age and income eligibility criteria are not so much of an issue, the medical eligibility standards can be. These standards can be quite restrictive, especially if they are condition or diagnosis based, and thus may exclude children with serious chronic conditions who may not have access to other sources of care for their health care needs. Behavioral conditions may be excluded altogether and unless they are serious enough to warrant care from another state agency, they may be left untreated or severely undertreated.

Second, even when SCHIP-covered CSHCN meet Title V eligibility criteria, eligibility for Title V services is subject to service and funding availability. Because Title V is a block grant,

funding for services is limited. In other words, if a Title V CSHCN agency runs out of funds, services are cut. Additionally, because Title V has a longstanding focus on physical disability and thus physical services, it is not surprising to find, as this study did, that Title V CSHCN programs generally exclude coverage of mental health and substance abuse services. To lessen the impact of these exclusions, at least half of the states have set up formal lines of referral between their separate SCHIP program/Title V CSHCN program and mental health and substance abuse programs in the state. Several states reported that, with the advent of SCHIP, coverage under SCHIP was extended to many children who were previously Title V agencies' responsibility, and thus freed up Title V resources that were previously allocated to these children. Because SCHIP coverage is limited for children who suffer from serious chronic conditions, Title V agencies could have invested these resources into adding or improving behavioral services. This research shows that such investments did not take place, keeping in line with the traditional role of these agencies.

Taken together, these findings have important implications for access to care by CSHCN in separate SCHIP programs but also for access to care by all children and adults with special needs who currently receive or will receive services under programs modified as a result of states' increased flexibility under the Administration's HIFA waiver policy, and possibly under the President's proposed Medicaid reforms.

First, states' experiences under SCHIP indicate that states will take advantage of the flexibility offered by the Administration's policy to scale back benefit packages and impose premiums and cost-sharing to make their public programs "look more like private insurance." This is not necessarily an issue for all individuals since most people are healthy and essentially require maintenance care, but it can be for individuals who have special needs that require services in amounts that exceed the norm.

Second, states' experiences in addressing the needs of CSHCN under SCHIP indicate that the majority of states have not focused their attention on individuals who may require services beyond those covered in the scaled back benefit packages, with only a handful having designed special programs to address the needs of such individuals.

Third, in states with special programs for CSHCN, individuals with certain health problems, such as behavioral conditions, still run the risk of lacking access to appropriate behavioral health care, unless there is an organized referral system to other state programs that furnish behavioral services.

Finally, even in states with an organized referral system to behavioral programs, families of children with special health care needs who qualify for services through a combination of SCHIP, Title V and behavioral health programs may find it time consuming and challenging to navigate these different systems of care in order to secure health services for their children. In addition, they may find that individuals with behavioral conditions for whom it is the only diagnosis may not qualify for existing mental health and substance abuse programs because their condition may not meet the severity criteria used by the programs as a condition of eligibility. These individuals would thus face the limitations of the SCHIP benefit package with nowhere else to turn for needed specialty care.

As an increasing number of states take advantage of a renewed flexibility under HIFA to re-design their Medicaid and SCHIP programs,[36] this study suggests that states may want to pay particular attention to children and adults with special needs. Mobilizing the multiple state agencies whose mission is to serve such individuals at the design stage to create a system

where these individuals can be directed to the appropriate sources of care, and coordinating the delivery of services at the implementation stage are two important lessons drawn from this research that will help ensure that fewer CSHCN and other individuals with special needs will fall through the cracks and more of them will receive services that will fill in the gaps left by the scaled back benefit packages under reengineered public health insurance programs.

APPENDIX

State-by-state profiles

The following pages provide state-by-state profiles of the six states that have made deliberate efforts to coordinate the administration of their SCHIP and Title V programs for the purpose of serving CSHCN. The profiles describe the following aspects of the two programs: any efforts to integrate and any changes brought to Title V subsequent to the implementation of the separate SCHIP program in the state based on a CHSRP survey of Title V CSHCN program representatives; comparative tables of enrollment, expenditures, and eligibility based on secondary analysis of existing documents; and comparative tables of services based on a CHSRP analysis of the separate SCHIP plans filed with the federal government and the same CHSRP survey of Title V CSHCN program representatives. Each state is categorized by the type of integration model it represents.

The “service supplement” model

Alabama

Estimated prevalence of CHSCN in the state: 173,341[37]

According to our respondent, CRS, Alabama's CSHCN program, worked with ALL-Kids, Alabama's SCHIP program, to develop ALL-Kids Plus, the SCHIP special benefit package for children with special health care needs. Children who are diagnostically eligible for CRS and financially eligible for SCHIP can receive enhanced benefits through ALL-Kids Plus. CRS pays the SCHIP match to support the delivery of the enhanced benefits. These benefits are beyond the scope of the ALL-Kids regular benefits but equal to the benefits received by other CSHCN in the CRS program. CRS does not fund primary care for children in its program. Furthermore, the Alabama SCHIP plan states that "with regard to ALL Kids Plus, the Department of Public Health, insurance vendors, and SEIB will work closely with ALL Kids Plus authorizing agencies, other CSHCN service providers, and disability advocacy groups to ensure that gaps in service and duplication of services are kept to a minimum."[38] Since Alabama's SCHIP program was implemented, CRS has expanded some coverage for ADL equipment and eye conditions based on the cost savings estimated to occur to the Title V CSHCN program due to the enactment of SCHIP. Over 400 SCHIP-covered CSHCN were covered as of October 2001.

Enrollment and Expenditures

	Separate SCHIP program[39]	Title V[40]
Total number of children served	49,008	259,143
Number of CSHCN served	9% (estimated)	22,300
Total expenditures	$75.1 million	$75.5 million
Expenditures on CSHCN	?	$16.9 million

Sources: Centers for Medicare and Medicaid Services, 2002; Maternal and Child Health Bureau, 2000.

Eligibility

	Separate SCHIP program[41]	Title V[42]
Age	0-19	0-21, except hemophiliacs who are covered beyond age 21.
Income	<200% FPL	Any child with a special health care need is financially eligible for services. Parents are asked to use ALL-Kids (Alabama's separate SCHIP program).
Condition	N/A But SCHIP-covered CSHCN must meet Title V criteria to obtain services through ALL-Kids Plus	Any child with a special health care need is eligible for services based on individual needs and the availability of the service within the agency. Eligible conditions include: cardiac conditions (excluding transplantation), cerebral palsy, cleft lip and palate, craniofacial conditions, cystic fibrosis, hearing loss, hemophelia, juvenile rheumatoid arthritis, neurosurgical/neurological conditions, orthopedic impairments, plastic surgical conditions, seizures, scoliosis, spina bifida, urological conditions, visual impairments.

Sources: GWU Center for Health Services Research and Policy, 2002; Centers for Medicare and Medicaid Services, 2002; Institute for Child Health Policy, 2000.

Services

	Separate SCHIP program	Title V
Lab and x-ray	√	√
Vision care	√	√
Hearing care	√	√
Home health services	√	√ (L)
Dental services	√	√ (L)
Physical therapy, occupational therapy, speech therapy	√	√
Prescriptions	√	√
Medical supplies	√	√
Durable medical equipment	√	√
Inpatient mental health services	√	
Outpatient mental health services	√	
Inpatient substance abuse services	√	
Outpatient substance abuse services	√	
Case management	√	
Care coordination	√	√
Medical transportation/Enabling transportation	√/√	√/√

KEY: √ = Explicitly covered; √ (L) = Explicitly covered with limitations; E = Explicitly excluded; Blank = State did not respond

NOTE: CRS provides the following services: appliances, assistive technology, audiological services, care coordination services, client/family education services, early intervention services, hospitalization, laboratory services, low vision services, medication, nursing services, nutritional counseling, occupational therapy, physician services, physical therapy, social work services, special dental/orthodontic services, speech/language therapy, surgery, and transportation reimbursement.

Source: GWU Center for Health Services Research and Policy Analysis of separate SCHIP plan filed with the federal administration and Survey of Title V CSHCN program, 2001; Institute for Child Health Policy, 2000.

Connecticut *Estimated prevalence of CHSCN in the state: 124,746*[43]

Children who are eligible for HUSKY Part B, Connecticut's separate SCHIP program, and who have special health care needs requiring intensive physical and behavioral health services receive medically necessary services under HUSKY Plus, which is composed of two supplemental insurance programs. One program, called HUSKY Plus Physical, supplements HUSKY Part B coverage for enrollees with intensive physical health needs and the other program, called HUSKY Plus Behavioral, supplements coverage for enrollees with intensive behavioral health needs. The physical health services are delivered through current Title V providers. More specifically, two Regional Centers, the Connecticut Children's Medical Center in Hartford and The Children's Hospital at Yale in New Haven, in conjunction with the Yale University School of Medicine, administer and coordinate HUSKY Plus Physical, but entities under contract to provide Title V services furnish the care.[44] The behavioral health services are organized by the Yale Child Study Center, which administers a statewide network of providers that includes most traditional community-based behavioral health providers.

According to our respondent**,** the Title V CSHCN program has made changes since the implementation of HUSKY Plus Physical (HPP). The major change relates to the target population served by the program. Prior to the implementation of HPP in 1998, the Title V CSHCN program covered children with or without a form of insurance provided the family met the program's financial and medical requirements. When HPP began, the Connecticut Title V CSHCN program transferred all of its enrollees without insurance to the HPP program and changed its focus to serving the underinsured. Currently, children who have some form of insurance (including Medicaid), meet the Maternal and Child Health Bureau's definition of a child with a special health care need, and have a family income of 300% FPL or less are eligible. Advocacy, family support and care coordination is available to any family/child with a special health care need regardless of insurance/enrollment status. The Title V CSHCN program does not cover primary care, but the child can be linked to a primary care provider if necessary.

When HPP was implemented, it was supposed to "mirror" the Title V CSHCN program. The Department of Public Health CSHCN staff and Department of Social Services HPP staff work in tandem. The Steering and Advisory Committee for CSHCN and HPP (SASH) was established shortly after HPP commenced. Both programs follow the same jointly developed protocols and covered services list. Title V CSHCN and HPP Center staff are housed together at the Connecticut Children's Medical Center and Yale locations and cover for each other if needed. HPP and Title V CSHCN have the same programmatic features. However, they are administered through two separate State Agencies each with its own requirements.

Enrollment and Expenditures

	Separate SCHIP program[45]	**Title V**[46]
Total number of children served	13,310	203,178
Number of CSHCN served	3%-8% (estimated)	5,284
Total funding/expenditures	$17.5 million	$11.9 million
Expenditures on CSHCN	?	$3.3 million

Sources: Centers for Medicare and Medicaid Services, 2002; Maternal and Child Health Bureau, 2000.

Eligibility

	Separate SCHIP program[47]	Title V[48]
Age	0-19	0-18, except no age limits for individuals with cystic fibrosis.
Income	<300% FPL	<300%FPL . Parents are asked to use HUSKY Part B (Connecticut's separate SCHIP program).
Condition	N/A But SCHIP-covered CSHCN must meet Title V criteria to obtain services through HUSKY Plus	Children who have or are at elevated risk for (biologic or acquired) chronic physical, developmental, behavioral, or emotional conditions and who also require health and related (not educational and not recreational) services of a type and amount not usually required by children of the same age.

Sources: GWU Center for Health Services Research and Policy, 2002; Centers for Medicare and Medicaid Services, 2002; Institute for Child Health Policy, 2000.

Services

	Separate SCHIP program	Title V
Lab and x-ray	√	√
Vision care	√	E
Hearing care	√(L)	√ (L)
Home health services	√	√ (L)
Dental services	√	√ (L)
Physical therapy, occupational therapy, speech therapy	√	√ (L)
Prescriptions	√	√
Medical supplies	√	√ (L)
Durable medical equipment	√	√
Inpatient mental health services	√ (L)	E
Outpatient mental health services	√ (L)	E
Inpatient substance abuse services	√ (L)	E
Outpatient substance abuse services	√ (L)	E
Case management	√	√
Care coordination	√	√
Medical transportation/Enabling transportation	√ (L)/ √	√/√ (L)

KEY: √ = Explicitly covered; √(L) = Explicitly covered with limitations; E = Explicitly excluded; Blank = State did not respond

NOTE: Services covered include: adaptive seating, specialized; audiometry; care planning; case room; dental (limited); diagnostic imaging (i.e., MRI, CT); durable medical equipment; EEG/telemetry; EKG/Halter; emergency care; family support, advocacy; hearing aids, digital and analog; home health aide; laboratory; medical nutrition services; medical 23 hour day; medical and day surgery; occupational therapy; orthodontics; orthotic devices; over the counter medication and/or medical surgical supplies; periodontal services; physical therapy; pharmacy; physician fees for inpatient care; physician fees for outpatient care (specialty); prosthetics/prosthetic devices; pulmonary function testing; radiology; skilled intermittent nursing; sleep study/polysomnography; special nutritional formulas; supplements/PKU foods; speech therapy; transportation; wheelchairs (including motorized). Title V excludes general dental care, inpatient hospital care, and routine pediatric care.

Source: GWU Center for Health Services Research and Policy Analysis of separate SCHIP plan filed with the federal administration and Survey of Title V CSHCN program, 2001; Institute for Child Health Policy, 2000.

North Carolina *Estimated prevalence of CHSCN in the state: 262,494*[49]

Children who are eligible for North Carolina's separate SCHIP program, and who have special health care needs requiring services beyond the scope, amount or duration covered under SCHIP receive Medicaid-equivalent benefits. The North Carolina Teachers' and State Employees' Comprehensive Major Medical Plan (TSECMMP) administers and processes claims for special needs children's acute medical care and other care.[50] Benefits over and above the basic benefit package are provided to CSHCN on a case-by-case basis by referral/appeal to the Special Needs (i.e., Title V CSHCN) program for consideration of coverage.[51] According to our respondent, the SCHIP program in North Carolina is a partnership between the Division of Medical Assistance, State Employee Health Plan, and the Division of Public Health (and Title V, which is a program of the Division of Public Health). Since the SCHIP program was implemented, the Title V CSHCN program has taken on the responsibility of coordinating the additional benefits and monitoring the quality of care provided to children with special health care needs enrolled in the SCHIP program. A full time staff person housed within the Title V program is responsible for these tasks. The state enabling legislation for SCHIP created the North Carolina Commission on Children with Special Health Care Needs to provide oversight in the development of the SCHIP program as it relates to CSHCN. This group is staffed by the Title V program. The Title V 1-800 Helpline has also devoted a significant amount of staff time to responding to calls related to enrolling or using benefits in the SCHIP program.

The CSHCN direct purchase of care program has been and continues to be a wrap-around benefit to Medicaid. Children enrolled in SCHIP cannot also be enrolled in Medicaid, and therefore cannot receive services from the purchase of care program. The SCHIP benefits package is modeled after the state employees health plan package, with additional benefits up to the level provided in Medicaid available for children with special health care needs, but there are a few types of services that children in Medicaid can receive through the purchase of care system that SCHIP-covered children cannot receive.

Enrollment and Expenditures

	Separate SCHIP program[52]	Title V[53]
Total number of children served	98,650	578,688
Number of CSHCN served	8% (estimated)	64,787
Total funding/expenditures	$133.5 million	$187 million
Expenditures on CSHCN	<$1 million	$54.6 million

Sources: Centers for Medicare and Medicaid Services, 2002; Maternal and Child Health Bureau, 2000.

Eligibility

	Separate SCHIP program[54]	Title V[55]
Age	0-19	0-21, except no age limits for individuals with cystic fibrosis and severe hemophilia.
Income	<200% FPL	<100% FPL for initial screening and for children who are not eligible for Medicaid coverage. Parents are asked to have Medicaid coverage for their children.
Condition	N/A	Children with specific chronic diseases or conditions that may hinder normal growth and development. Examples: birth defects, cancer, blood disorders, and orthopedic impairments. Medical director has authority to approve coverage for children with other diseases or conditions.

Sources: GWU Center for Health Services Research and Policy, 2002; Centers for Medicare and Medicaid Services, 2002; Institute for Child Health Policy, 2000.

Services

	Separate SCHIP program	Title V
Lab and x-ray	√	√
Vision care	√ (L)	
Hearing care	√	√
Home health services	√ (L)	
Dental services	√ (L)	√ (L)
Physical therapy, occupational therapy, speech therapy	√	E
Prescriptions	√	√
Medical supplies	√ (L)	√
Durable medical equipment	√ (L)	√
Inpatient mental health services	√	E
Outpatient mental health services	√ (L)	E
Inpatient substance abuse services	√	E
Outpatient substance abuse services	√ (L)	E
Case management	√	
Care coordination	√	√
Medical transportation/Enabling transportation	√/E	

KEY: √ = Explicitly covered; √(L) = Explicitly covered with limitations; E = Explicitly excluded; Blank = State did not respond

NOTE: All Title V services have limitations on some level. Eligible services subject to availability of resources include: audiology services, assistive technology services, drugs and special formulas, emergency room visits, equipment and supplies, inpatient hospitalization, laboratory tests, limited nursing visits, nutrition services, orthodontia for children with oral facial disorders, physician services, and surgery. In addition, some services in the chart are not covered by Title V because they are paid for by another state agency (e.g., mental health and substance abuse services). Others are covered by Medicaid (e.g., physical therapy, occupational therapy, and speech therapy) and therefore do not need to be covered by the Title V program.

Source: GWU Center for Health Services Research and Policy Analysis of separate SCHIP plan filed with the federal administration and Survey of Title V CSHCN program, 2001; Institute for Child Health Policy, 2000.

The “specialty care carve-out” model

California

Estimated prevalence of CHSCN in the state: 1,276,705[56]

The Managed Risk Medical Insurance Board (MRMIB), the oversight agency for Healthy Families, encourages the SCHIP program to develop protocols to screen and refer children needing services beyond the scope of the program's benefit package to public programs providing such services and to coordinate care between the plan and the public programs.[57] Under Healthy Families, California's separate SCHIP program, children, including CSHCN, receive similar benefits to those provided to state employees under the California Public Employees Retirement System, better known as CalPERS. CSHCN may receive further treatment in a non-managed care delivery system run by California Children Services (CCS), the state's Title V CSHCN agency. As described in the state SCHIP plan, "services needed by 'special needs' children, but not provided by health plans, [are] provided through a specialized delivery system under the CCS program. Mental health services provided to severely emotionally disabled children [are] provided through the county mental health departments with referral and coordination with the health plans…"[58]

According to our respondent, CCS has made changes to its program since the implementation of Healthy Families, including improved coverage of maintenance and transportation, and inclusion of SCHIP eligibility determination in its automated case management system. The program has also developed memoranda of understanding between the health plans participating in the SCHIP program and the county health departments that provide the case management for the eligible conditions carved out of the health plans. The CCS program provides some services above those offered by the SCHIP plan related to the eligible conditions (e.g., therapy, transportation), functions as a specialty care "carve-out" program, and approves and enrolls specialty care providers into the CCS system.

Enrollment and Expenditures

	Separate SCHIP program[59]	Title V[60]
Total number of children served	634,472	2.9 million
Number of CSHCN served	1% (estimated)	133,007
Total funding/expenditures	$476.1 million	$1,107.6 million
Expenditures on CSHCN	?	$912.7 million

Sources: Centers for Medicare and Medicaid Services, 2002; Maternal and Child Health Bureau, 2000.

Eligibility

	Separate SCHIP program[61]	Title V[62]
Age	0-19	0-21
Income	<250% FPL	Persons in families with an adjusted gross income of $40,000 or less in the most recent tax year, and persons in families with an adjusted gross income of over $40,000 if the estimated cost of out-of-pocket expenditures for medical care for the child will exceed 20% of adjusted gross income. Available regardless of income: initial diagnostic and evaluation services for all children; case management services for Medicaid and Healthy Families (California's separate SCHIP program) covered children with an eligible medical condition.
Condition	N/A But children who have health insurance through Healthy	All serious medical conditions of a physical nature that can be cured, improved or stabilized. Eligible medical conditions include birth defects (such as congenital

	Separate SCHIP program[61]	Title V[62]
	Families may be eligible for CCS coverage for care related to a CCS medically eligible condition	heart disease); chronic illnesses (such as cystic fibrosis); malignancies and certain serious injuries and physical disabilities. Exclusions: Acute neuritis and neuralgia; avitaminosis and other dietary deficiency diseases causing "failure to thrive" (except rickets) and exogenous obesity; infective and parasitic diseases unless they involve the bone, eyes, and may lead to blindness, or the central nervous system and produce disabilities requiring surgical or rehabilitative services; learning disabilities, educational handicaps, minimal cerebral dysfunction; and behavior problems; meningitis and communicable disease involving the nervous system without disability or sequelae; mental disorders and mental retardation when they are the only diagnosis; migraine; minor orthopedic conditions.

Sources: GWU Center for Health Services Research and Policy, 2002; Centers for Medicare and Medicaid Services, 2002; Institute for Child Health Policy, 2000.

Services

	Separate SCHIP program	Title V
Lab and x-ray	√	√
Vision care	√	√ (L)
Hearing care	√	√
Home health services	√ (L)	√
Dental services	√ (L)	√
Physical therapy, occupational therapy, speech therapy	√ (L)	√
Prescriptions	√ (L)	√
Medical supplies	√ (L)	√
Durable medical equipment	√ (L)	√
Inpatient mental health services	√ (L)	√ (L)
Outpatient mental health services	√ (L)	√ (L)
Inpatient substance abuse services	√	
Outpatient substance abuse services	√ (L)	
Case management	E	√ (L)
Care coordination	E	√ (L)
Medical transportation/Enabling transportation	√ /E	√ (L) /√ (L)

KEY: √ = Explicitly covered; √ (L) = Explicitly covered with limitations; E = Explicitly excluded; Blank = State did not respond

Source: GWU Center for Health Services Research and Policy Analysis of separate SCHIP plan filed with the federal administration and Survey of Title V CSHCN program, 2001; Institute for Child Health Policy, 2000.

The “person carve-out” model

Florida

Estimated prevalence of CHSCN in the state: 469,647[63]

The Children's Medical Services (CMS) Network is a statewide managed care system for low-income CSHCN. It is a required managed care option for Medicaid and SCHIP-covered children who have special health care needs, and it is available as the CMS Safety Net Program for CSHCN who do not qualify for either SCHIP or Medicaid. It provides comprehensive benefits, including early intervention programs, primary care for CSHCN, regionalized specialty services, and long term care. Providers and families are supported through a case management system.

Following the initial implementation of KidCare, Florida's SCHIP program, which expanded Medicaid to adolescents under 100 percent of the federal poverty level and expanded Florida's existing Healthy Kids program for school-aged children statewide, Florida expanded eligibility for premium subsidies under Healthy Kids to 200 percent of the federal poverty level and added, as integral components of KidCare, the MediKids program for children too young to be in school and the CMS Network for children who have special health care needs. The state later expanded Medicaid coverage to infants under 200 percent of the federal poverty level and eliminated coverage for this group under MediKids and the Title XXI CMS Network. Thus, for SCHIP-eligible children who have special health care needs and meet the CMS eligibility criteria, the CMS Network covers children ages 1 through 5 with family incomes between 133 and 200 percent of the federal poverty level and children age 6 and older with family incomes between 100 and 200 percent of the federal poverty level.

Because Florida law provides for a child with a special health care need to be referred to the CMS Network, the KidCare application form contains a screening question to determine whether a child has a special health care need.[64] If the answer to this question is yes, the child is referred to the CMS program for a medical eligibility determination.[65] If the child is eligible, the CMS program enrolls the child in the CMS Network; if the child is not eligible for the CMS Network, the child is enrolled in MediKids or Healthy Kids depending on his age.[66] Severely emotionally disturbed (SED) children (as classified by their local school districts) are referred to CMS and the Department of Children and Families's local staff for a determination of eligibility for specialized behavioral health care services.[67] If eligible, these children receive non-behavioral services through the CMS Network, and, subject to the availability of treatment slots, behavioral services through networks of providers overseen by the Department of Children and Families under an agreement between CMS and the Department of Children and Families.[68] Children enrolled in the CMS Network receive the same benefits as those offered under Medicaid, except for Medicaid waiver services.[69] The CMS program sends a monthly bill to the Agency for Health Care Administration for capitation payments for CMS Network participants, and makes similar requests separately for services provided to children with SED.[70]

Enrollment and Expenditures

	Separate SCHIP program[71]	Title V[72]
Total number of children served	282,879	579,144
Number of CSHCN served	3%-5% (estimated)	47,581 (14% are Title XXI)
Total funding/expenditures	$308.8 million	$296 million
Expenditures on CSHCN	?	$102.7 million

Sources: Centers for Medicare and Medicaid Services, 2002; Maternal and Child Health Bureau, 2000.

Eligibility

	Separate SCHIP program[73]	Title V[74]
Age	1-19	0-21
Income	<200% FPL	Medicaid-covered pregnant women and infants <200% FPL; children ages 1-6 <133% FPL; children ages 6-21 <100% FPL. SCHIP-covered children 1-19 <200% FPL. Other children ages 0-21 not eligible for Medicaid nor SCHIP <200% FPL. Regardless of income: initial screening services.
Condition	N/A But state law provides for a child with a special health care need to be referred to the Children's Medical Services Network	Children whose serious, chronic physical or developmental conditions require extensive preventive and maintenance care beyond that required by typically healthy children.

Sources: GWU Center for Health Services Research and Policy, 2002; Centers for Medicare and Medicaid Services, 2002; Institute for Child Health Policy, 2000.

Services

	Separate SCHIP program	Title V
Lab and x-ray	√	
Vision care	√	
Hearing care	√	
Home health services	√	
Dental services	√ (L)	
Physical therapy, occupational therapy, speech therapy	√	
Prescriptions	√	
Medical supplies	√	
Durable medical equipment	√	
Inpatient mental health services	√ (L)	
Outpatient mental health services	√ (L)	
Inpatient substance abuse services	√ (L)	
Outpatient substance abuse services	√ (L)	
Case management	E	√
Care coordination	E	√
Medical transportation/Enabling transportation	√ (L)/E	

KEY: √ = Explicitly covered; √ (L) = Explicitly covered with limitations; E = Explicitly excluded; Blank = State did not respond

NOTE: Benefits include medically necessary treatment, including case management and care coordination, preventive and early intervention services, benefits covered by the Medicaid and the SCHIP program, and other medically necessary services.

Source: GWU Center for Health Services Research and Policy Analysis of separate SCHIP plan filed with the federal administration and Survey of Title V CSHCN program, 2001; Institute for Child Health Policy, 2000.

Michigan

Estimated prevalence of CHSCN in the state: 414,105[75]

Under Children's Special Health Care Services (CSHCS), Michigan's Title V program, children eligible for the program who are not eligible for Medicaid and who do not have another source of coverage can choose to enroll in either (1) MIChild, the state's separate SCHIP program, which includes specialty services, (2) the CSHCS managed care program, known as the Special Health Plan, with optional supplemental primary coverage to ensure that all services available under MIChild are covered through the CSHCS managed care plan, or (3) the fee-for-service CSHCS program for specialty care only. If the family chooses MIChild, the child is disenrolled from CSHCS; if the family chooses the Special Health Plan, the child is enrolled with a CSHCS managed care provider for the specialty services and supplemental primary coverage; and if the family chooses the fee-for-service CSHCS program, the child has specialty coverage only through CSHCS.[76]

The Special Health Plan, made available in 1998 to CHSCN who also had Medicaid, was extended to MIChild-eligible children when the program was designed and implemented. The state's Administrative Contractor responsible for MIChild enters into a cooperative written agreement with the CSHCS Eligibility Division, which includes provisions regarding referrals for potential CSHCS eligible children and enrollment in the Special Health Plan for comprehensive health care.[77] Under the program, selected contractors (there are two Special Health Plans, Kids Care of Michigan and Children's Choice of Michigan) provide health care specifically tailored to special needs on a capitated basis (capitation rates are set at levels that adjust for the higher needs of CHSCN) to children who participate in the CSHCS program, whether they have CSHCS coverage only, Medicaid coverage, or MIChild coverage. CSHCN who have either Medicaid or MIChild receive comprehensive health care coverage and coordination of their services and benefits, including those excluded from the Special Health Plan contract. Each child participates in a renewable, annual Individualized Health Care Plan that identifies within the first two months of enrollment all of the known and anticipated services the child will likely need in the following year, as a means to bypass the need for referrals within the Special Health Plan during that time period. As of July 2000, 2,015 CSHCN were enrolled in a Special Health Plan.

Enrollment and Expenditures

	Separate SCHIP program[78]	Title V[79]
Total number of children served	34,247	2,667,708
Number of CSHCN served	2% (estimated)	27,550
Total funding/expenditures	53,067,535	$102.5 million
Expenditures on CSHCN	?	$34.1 million

Sources: Centers for Medicare and Medicaid Services, 2002; Maternal and Child Health Bureau, 2000.

Eligibility

	Separate SCHIP program[80]	Title V[81]
Age	0-19	0-21, except for individuals with cystic fibrosis or coagulation defects for whom services are extended beyond age 21.
Income	<200% FPL	Full coverage regardless of income. No financial participation required if the child is in MIChild (Michigan's separate SCHIP program).
Condition	N/A	Factors considered in making a determination of eligibility for Children's Special Health Care Services (CSHCS) include type of condition (diagnosis),

	Separate SCHIP program[80]	Title V[81]
		severity of the condition, long-term effects of the condition on the child and family, and the treatment plan recommended by CSHCS specialists (need for specialty treatment). CSHCS covers more than 2,700 diagnoses. Eligible diagnostic groups include: certain diseases peculiar to newborn infants; congenital anomalies; diseases of the blood and blood forming organs; diseases of the circulatory system; diseases of the digestive system; diseases of the genitourinary system; diseases of the musculoskeletal system and connective tissue; diseases of the nervous system and sense organs; diseases of the respiratory system; diseases of the skin and subcutaneous tissue; endocrinal, nutritional and metabolic diseases; infective and parasitic diseases; injury and poisoning; neoplasms. Excluded conditions: autism; dyslexia; emotional disorders; learning disabilities; mental retardation.

Sources: GWU Center for Health Services Research and Policy, 2002; Centers for Medicare and Medicaid Services, 2002; Institute for Child Health Policy, 2000.

Services

	Separate SCHIP program	Title V
Lab and x-ray	√	√
Vision care	√ (L)	√
Hearing care	√ (L)	√
Home health services	√ (L)	√
Dental services	√ (L)	√ (L)
Physical therapy, occupational therapy, speech therapy	√	√
Prescriptions	√ (L)	√
Medical supplies	√	√
Durable medical equipment	√	√
Inpatient mental health services	√	E
Outpatient mental health services	√	E
Inpatient substance abuse services	√	
Outpatient substance abuse services	√	
Case management	√ (L)	√
Care coordination	√ (L)	√
Medical transportation/Enabling transportation	√ /E	

KEY: √ = Explicitly covered; √ (L) = Explicitly covered with limitations; E = Explicitly excluded; Blank = State did not respond

NOTE: CSHCS also covers inpatient hospitalization, nutrition counseling, outpatient care, respite nursing care, surgery; it excludes experimental care (certain organ transplants), medical social work, mental health and skilled nursing and intermediate care facilities.

Source: GWU Center for Health Services Research and Policy Analysis of separate SCHIP plan filed with the federal administration and Survey of Title V CSHCN program, 2001; Institute for Child Health Policy, 2000.

ENDNOTES

[1] States must limit coverage to targeted low-income children who are ineligible for Medicaid or other creditable coverage. States have the option of setting income eligibility levels (i) between the upper, state-defined Medicaid eligibility level for children and 200% FPL or (ii) 50 percentage points higher than the upper, state-defined Medicaid eligibility level if that level is set higher than 200% FPL. 42 U.S.C. §1397jj(b) and (c)(4); 42 C.F.R. §457.10.
[2] 42 U.S.C. §1397jj(c)(2); 42 C.F.R. §457.10.
[3] Rosenbaum, S., Markus, A., Sonosky, C., and Repasch, L. (2001) "State Benefit Design Choices under SCHIP: Implications for Pediatric Health Care." SCHIP Policy Brief #2 Washington, D.C.: Center for Health Services Research and Policy, School of Public Health and Health Services, The George Washington University; Rosenbaum, S., Markus, A., and Roby, D. (1999) An Analysis of Implementation Issues Relating to CHIP Cost-sharing Provisions for Certain Targeted Low Income Children . Bethesda, MD, and Baltimore, MD: Health Resources and Services Administration and Health Care Financing Administration, Department of Health and Human Services. At www.gwhealthpolicy.org.
[4] Rosenbaum *et al*, *op.cit.* (2001). See also, e.g., Hill, I., Lutzky, A., and Schwalberg, R. (2001) Are We Responding to Their Needs? States' Early Experiences Serving Children with Special Health Care Needs under SCHIP Washington, D.C.: The Urban Institute; Pernice, C., Wysen, K., Riley, T., and Kaye, N. (2001) Charting SCHIP: Report of the Second National Survey of the State Children's Health Insurance Program. Portland, ME: National Academy for State Health Policy; Fox, H., McManus, P., and Limb, S. (2000) Access to Care for S-CHIP Children with Special Health Needs Washington, D.C.: The Kaiser Commission on Medicaid and the Uninsured; Schwalberg, R., Mathis, S., and Hill, I. (2000) New Opportunities, New Approaches: Serving Children with Special Health Care Needs under SCHIP, Los Altos, CA: The David and Lucile Packard Foundation; O'Brien, M.J. *et al.* (2000) "State Experiences with Access Issues under Children's Health Insurance Expansions" Field Report New York, NY: The Commonwealth Fund; Fox, H. (1999) "An Analysis of States' CHIP Policies Affecting Children with Special Health Care Needs" Issue Brief, No. 5, Washington, D.C.: Maternal and Child Health Policy Research Center and Fox Health Policy Consultants.
[5] Rosenbaum *et al*, *op.cit.* (2001).
[6] Rosenbaum, S., and Sonosky, C. (2000) Federal EPSDT Coverage Policy: An Analysis of State Medicaid Plans and Medicaid Managed Care Contracts Washington, D.C.: Center for Health Services Research and Policy, School of Public Health and Health Services, The George Washington University.
[7] An earlier and similarly structured program, the Sheppard-Towner Act was passed by Congress in 1921 but repealed eight years later in response to the active opposition by the American Medical Association. It was disagreement on the part of pediatricians with the position of the AMA that led to the establishment of the American Academy of Pediatrics.
[8] MCHB. (2000) Title V—A Snapshot of Maternal and Child Health 2000 Rockville, MD: Health Resources and Services Administration, U.S. Department of Health and Human Services.
[9] MCHB, *op. cit.*
[10] MCHB, *op. cit.*
[11] MCHB, *op. cit.*
[12] These programs include the following: rehabilitation services for children receiving Supplemental Security Income, services to screen and identify children for lead poisoning, programs to identify generic diseases, programs to detect and manage sudden infant death syndrome, hemophilia treatment for children, and adolescent pregnancy prevention programs. In Rosenbaum *et al.* (2002) Using the Title Maternal and Child Health Services Block Grant to Support Child Development Services New York, NY: The Commonwealth Fund. At www.cmwf.org or www.gwhealthpolicy.org
[13] Rosenbaum *et al., op.cit.*(2002).
[14] See M. McPherson *et al.*, "A New Definition of Children with Special Health Care Needs," 102 *Pediatrics* 1137-40 (1998). This definition is used under the Title V Maternal and Child Health Services Block Grant program, 42 U.S.C. §701 *et seq*.
[15] Rosenbaum *et al., op.cit.* (2002).
[16] MCHB, *op. cit.*
[17] Association of Maternal and Child Health Programs, 2002.
[18] mchb.hrsa.gov.
[19] Other specific purposes include: (1) to assure access to quality MCH services; (2) to reduce infant and child morbidity and mortality, and the need for inpatient care and institutional care; (3) to promote the health of mothers and children; (4) to provide prenatal, delivery and postpartum care; (5) to provide preventive and primary care services. In Rosenbaum *et al.* (2001); Treeby Williamson Brown (1999) The History of Title V & Current Challenges, Washington, D.C.: Association of Maternal and Child Health Programs.
[20] Williamson Brown, *op.cit.*
[21] Rosenbaum *et al., op.cit.* (2002, Appendix B).
[22] Rosenbaum *et al., op.cit.* (2002, Appendix B).

[23] Rosenbaum *et al., op.cit.* (2002) Note that if a physician finds that a particular service excluded from Medicaid (e.g., dental care) is medically necessary for a Medicaid-covered child under the EPSDT coverage standard, that service should be provided regardless of whether it is explicitly listed as a covered benefit.
[24] Sec. 2102(c)(2) of the Social Security Act; 42 U.S.C. 1397bb(c)(2) Note that a similar requirement exists in Title V for state Title V agencies to coordinate with Medicaid, SCHIP, SSI, WIC, family planning, education, developmental disability and other related programs.
[25] 42 C.F.R. 457.80(c)
[26] Rosenbaum *et al., op.cit.* (2002)
[27] Institute for Child Health Policy. (2000) Directory of State Title V CSHCN Programs Eligibility Criteria and Scope of Services Eds. Reiss, J., and Lamar, D. Gainesville, FL: State University System of Florida Accessed 2/23/01 at cshcnleaders.ichp.edu/Title Vdirectory/default.htm.
[28] See, e.g., Hill, I., Lutzky, A., and Schwalberg, R. (2001) Are We Responding to Their Needs? States' Early Experiences Serving Children with Special Health Care Needs under SCHIP Washington, D.C.: The Urban Institute; Pernice, C., Wysen, K., Riley, T., and Kaye, N. (2001) Charting SCHIP: Report of the Second National Survey of the State Children's Health Insurance Program. Portland, ME: National Academy for State Health Policy; Fox, H., McManus, P., and Limb, S. (2000) Access to Care for S-CHIP Children with Special Health Needs Washington, D.C.: The Kaiser Commission on Medicaid and the Uninsured; Schwalberg, R., Mathis, S., and Hill, I. (2000) New Opportunities, New Approaches: Serving Children with Special Health Care Needs under SCHIP, Los Altos, CA: The David and Lucile Packard Foundation; O'Brien, M.J. *et al.* (2000) "State Experiences with Access Issues under Children's Health Insurance Expansions" Field Report New York, NY: The Commonwealth Fund; Fox, H. (1999) "An Analysis of States' CHIP Policies Affecting Children with Special Health Care Needs" Issue Brief, No. 5, Washington, D.C.: Maternal and Child Health Policy Research Center and Fox Health Policy Consultants.
[29] Hill, I. *et al.*, 2001, *op. cit.*
[30] *Ibid.*
[31] Massachusetts is another state identified as having made a concerted effort to address the needs of CSHCN during the design of SCHIP (the state had a previously established state-funded program for disabled children and adults ineligible for Medicaid which was integrated into MassHealth, as was SCHIP) but because the state's Title V agency is not directly involved in the administration of the program, we excluded the state from this study. According to our respondent, Massachusetts's separate SCHIP program, MassHealth Family Assistance, has been integrated into the Medicaid expansion known as MassHealth that was already ongoing in Massachusetts when the federal SCHIP law was passed. It does not, therefore, operate like a discrete program and it has not resulted in any changes in the Title V program, which continues to assist families in obtaining and coordinating publicly financed services, such as those provided under MassHealth. The Division of Medical Assistance is the single state agency in Massachusetts that administers Medicaid (MassHealth Standard) and the Children's Health Insurance Program (MassHealth Family Assistance), which are combined into one program called MassHealth. Also part of MassHealth is MassHealth CommonHealth, a health plan for adults and children with disabilities who are not eligible for MassHealth Standard (Medicaid). CommonHealth is a wrap-around program that pays for services excluded from other sources of health insurance disabled adults and children may have. MassHealth Family Assistance provides direct coverage for uninsured children who are not eligible for Standard or CommonHealth or through premium assistance for children who have access to and enroll in private health insurance. A fourth and final component of MassHealth is Prenatal for pregnant women. Eligibility for each MassHealth component is determined by the income of the family group, the presence of a disability or pregnancy, and the availability of health insurance.
[32] Rosenbaum, S, Markus, A.R., and Roby, D. (1999) An Analysis of Implementation Issues Relating to CHIP Cost-Sharing Provisions for Certain Targeted Low-income Children. Bethesda, MD and Baltimore, MD: Health Resources and Services Administration and the Health Care Financing Administration, Department of Health and Human Services. At www.hcfa.gov or www.gwhealthpolicy.org.
[33] This assumes a midpoint estimate between 15 and 18 percent of all children under age 18.
[34] These data are for FY 1998.
[35] *Ibid.*
[36] Three states (Arizona, California, Utah) received approval of their HIFA waiver request as of February 2002.
[37] Family Voices. "Children with Special Health Care Needs Estimated Prevalence by State" Fact Sheet Accessed 3/7/02 at www.familyvoices.org/chscn1.html This estimate is based on generally accepted definitions of children with special health care needs and on data from 1990 and 1994.
[38] Alabama SCHIP plan, p. 26.
[39] Centers for Medicare and Medicaid Services. (2002) The State Children's Health Insurance Program –Fiscal Year 2001 Annual Enrollment Report Accessed 3/7/02 at www.hcfa.gov/init (Note: Enrollment information is for FY 2001, i.e. 10/1/2000-9/30/2001); Centers for Medicare and Medicaid Services. "Alabama Title XXI State Program" Fact Sheet Accessed 3/7/02 at www.hcfa.gov/init/chpafsal.htm (Note: Financial information is for FY 2002)
[40] Maternal and Child Health Bureau. (2000) Title V A Snapshot of Maternal and Child Health 2000 Rockville, MD: Health Resources and Services Administration, U.S. Department of Health and Human Services (Note: Data is for FY 98)

[41] Centers for Medicare and Medicaid Services. "Alabama Title XXI State Program" Fact Sheet Accessed 3/7/02 at www.hcfa.gov/init/chpafsal.htm (Note: Financial information is for FY 2002).
[42] Institute for Child Health Policy. (2000) Directory of State Title V CSHCN Programs Eligibility Criteria and Scope of Services Eds. Reiss, J., and Lamar, D. Gainesville, FL: State University System of Florida Accessed 2/23/01 at cshcnleaders.ichp.edu/Title Vdirectory/default.htm.
[43] Family Voices. "Children with Special Health Care Needs Estimated Prevalence by State" Fact Sheet Accessed 3/7/02 at www.familyvoices.org/chscn1.html This estimate is based on generally accepted definitions of children with special health care needs and on data from 1990 and 1994.
[44] The Title V CSHCN program, originally run by CSHCN State staff, was outsourced in 1997 to the Connecticut Children's Medical Center and Yale.
[45] Centers for Medicare and Medicaid Services. (2002) The State Children's Health Insurance Program –Fiscal Year 2001 Annual Enrollment Report Accessed 3/7/02 at www.hcfa.gov/init (Note: Enrollment information is for FY 2001, i.e. 10/1/2000-9/30/2001); Centers for Medicare and Medicaid Services. "Connecticut Title XXI State Program" Fact Sheet Accessed 3/7/02 at www.hcfa.gov/init/chpafsal.htm (Note: Financial information is for FY 2002).
[46] Maternal and Child Health Bureau. (2000) Title V A Snapshot of Maternal and Child Health 2000 Rockville, MD: Health Resources and Services Administration, U.S. Department of Health and Human Services (Note: Data is for FY 98).
[47] Centers for Medicare and Medicaid Services. "Connecticut Title XXI State Program" Fact Sheet Accessed 3/7/02 at www.hcfa.gov/init/chpafsal.htm (Note: Financial information is for FY 2002).
[48] Institute for Child Health Policy. (2000) Directory of State Title V CSHCN Programs Eligibility Criteria and Scope of Services Eds. Reiss, J., and Lamar, D. Gainesville, FL: State University System of Florida Accessed 2/23/01 at cshcnleaders.ichp.edu/Title Vdirectory/default.htm.
[49] Family Voices. "Children with Special Health Care Needs Estimated Prevalence by State" Fact Sheet Accessed 3/7/02 at www.familyvoices.org/chscn1.html This estimate is based on generally accepted definitions of children with special health care needs and on data from 1990 and 1994.
[50] North Carolina SCHIP plan, unnumbered pages [on-line].
[51] *Ibid.*
[52] Centers for Medicare and Medicaid Services. (2002) The State Children's Health Insurance Program –Fiscal Year 2001 Annual Enrollment Report Accessed 3/7/02 at www.hcfa.gov/init (Note: Enrollment information is for FY 2001, i.e. 10/1/2000-9/30/2001); Centers for Medicare and Medicaid Services. "North Carolina Title XXI State Program" Fact Sheet Accessed 3/7/02 at www.hcfa.gov/init/chpafsal.htm (Note: Financial information is for FY 2002).
[53] Maternal and Child Health Bureau. (2000) Title V A Snapshot of Maternal and Child Health 2000 Rockville, MD: Health Resources and Services Administration, U.S. Department of Health and Human Services (Note: Data is for FY 98).
[54] Centers for Medicare and Medicaid Services. "North Carolina Title XXI State Program" Fact Sheet Accessed 3/7/02 at www.hcfa.gov/init/chpafsal.htm (Note: Financial information is for FY 2002).
[55] Institute for Child Health Policy. (2000) Directory of State Title V CSHCN Programs Eligibility Criteria and Scope of Services Eds. Reiss, J., and Lamar, D. Gainesville, FL: State University System of Florida Accessed 2/23/01 at cshcnleaders.ichp.edu/Title Vdirectory/default.htm.
[56] Family Voices. "Children with Special Health Care Needs Estimated Prevalence by State" Fact Sheet Accessed 3/7/02 at www.familyvoices.org/chscn1.html This estimate is based on generally accepted definitions of children with special health care needs and on data from 1990 and 1994.
[57] California SCHIP plan, p. 14-15.
[58] California SCHIP plan, Attachment 6, .p.1.
[59] Centers for Medicare and Medicaid Services. (2002) The State Children's Health Insurance Program –Fiscal Year 2001 Annual Enrollment Report Accessed 3/7/02 at www.hcfa.gov/init (Note: Enrollment information is for FY 2001, i.e. 10/1/2000-9/30/2001); Centers for Medicare and Medicaid Services. "California Title XXI State Program" Fact Sheet Accessed 3/7/02 at www.hcfa.gov/init/chpafsal.htm (Note: Financial information is for FY 2002).
[60] Maternal and Child Health Bureau. (2000) Title V A Snapshot of Maternal and Child Health 2000 Rockville, MD: Health Resources and Services Administration, U.S. Department of Health and Human Services (Note: Data is for FY 98).
[61] Centers for Medicare and Medicaid Services. "California Title XXI State Program" Fact Sheet Accessed 3/7/02 at www.hcfa.gov/init/chpafsal.htm (Note: Financial information is for FY 2002).
[62] Institute for Child Health Policy. (2000) Directory of State Title V CSHCN Programs Eligibility Criteria and Scope of Services Eds. Reiss, J., and Lamar, D. Gainesville, FL: State University System of Florida Accessed 2/23/01 at cshcnleaders.ichp.edu/Title Vdirectory/default.htm.
[63] Family Voices. "Children with Special Health Care Needs Estimated Prevalence by State" Fact Sheet Accessed 3/7/02 at www.familyvoices.org/chscn1.html This estimate is based on generally accepted definitions of children with special health care needs and on data from 1990 and 1994.
[64] Florida SCHIP plan, p. 23, 24, 27.
[65] Florida SCHIP plan, p. 27.

[66] *Ibid.*
[67] *Ibid.*
[68] Florida SCHIP plan, p. 20-22.
[69] Florida SCHIP plan, p. 17, 42.
[70] Florida SCHIP plan, p. 71.
[71] Centers for Medicare and Medicaid Services. (2002) The State Children's Health Insurance Program –Fiscal Year 2001 Annual Enrollment Report Accessed 3/7/02 at www.hcfa.gov/init (Note: Enrollment information is for FY 2001, i.e. 10/1/2000-9/30/2001); Centers for Medicare and Medicaid Services. "Florida Title XXI State Program" Fact Sheet Accessed 3/7/02 at www.hcfa.gov/init/chpafsal.htm (Note: Financial information is for FY 2002).
[72] Maternal and Child Health Bureau. (2000) Title V A Snapshot of Maternal and Child Health 2000 Rockville, MD: Health Resources and Services Administration, U.S. Department of Health and Human Services (Note: Data is for FY 98).
[73] Centers for Medicare and Medicaid Services. "Florida Title XXI State Program" Fact Sheet Accessed 3/7/02 at www.hcfa.gov/init/chpafsal.htm (Note: Financial information is for FY 2002).
[74] Institute for Child Health Policy. (2000) Directory of State Title V CSHCN Programs Eligibility Criteria and Scope of Services Eds. Reiss, J., and Lamar, D. Gainesville, FL: State University System of Florida Accessed 2/23/01 at cshcnleaders.ichp.edu/Title Vdirectory/default.htm.
[75] Family Voices. "Children with Special Health Care Needs Estimated Prevalence by State" Fact Sheet Accessed 3/7/02 at www.familyvoices.org/chscn1.html This estimate is based on generally accepted definitions of children with special health care needs and on data from 1990 and 1994.
[76] Michigan SCHIP plan, p.19.
[77] Michigan SCHIP plan, Attachment to April 16, 1998 memo, p. 14.
[78] Centers for Medicare and Medicaid Services. (2002) The State Children's Health Insurance Program –Fiscal Year 2001 Annual Enrollment Report Accessed 3/7/02 at www.hcfa.gov/init (Note: Enrollment information is for FY 2001, i.e. 10/1/2000-9/30/2001); Centers for Medicare and Medicaid Services. "Michigan Title XXI State Program" Fact Sheet Accessed 3/7/02 at www.hcfa.gov/init/chpafsal.htm (Note: Financial information is for FY 2002).
[79] Maternal and Child Health Bureau. (2000) Title V A Snapshot of Maternal and Child Health 2000 Rockville, MD: Health Resources and Services Administration, U.S. Department of Health and Human Services (Note: Data is for FY 98).
[80] Centers for Medicare and Medicaid Services. "Michigan Title XXI State Program" Fact Sheet Accessed 3/7/02 at www.hcfa.gov/init/chpafsal.htm (Note: Financial information is for FY 2002).
[81] Institute for Child Health Policy. (2000) Directory of State Title V CSHCN Programs Eligibility Criteria and Scope of Services Eds. Reiss, J., and Lamar, D. Gainesville, FL: State University System of Florida Accessed 2/23/01 at cshcnleaders.ichp.edu/Title Vdirectory/default.htm.

1330 G Street NW, Washington, DC 20005
Phone: (202) 347-5270, *Fax:* (202) 347-5274
Website: www.kff.org/KCMU

Additional copies of this report (#7035) are available
on the Kaiser Family Foundation's website at www.kff.org.