

SCHIP ENROLLEES WITH SPECIAL HEALTH CARE NEEDS AND ACCESS TO CARE

The State Children's Health Insurance Program (SCHIP) provides health insurance coverage to low-income children whose families earn too much income to be eligible for Medicaid but lack private health insurance. States can choose to expand Medicaid, create a separate program that may have eligibility rules and coverage different from Medicaid, or establish a combination program. Numerous factors, such as restrictions on health care coverage and insufficient provider participation, can limit access to care for children enrolled in public insurance programs. These factors can be especially burdensome for children with special health care needs (CSHCN)—a group of children who typically require a level of health care beyond that of other enrollees.

This Child Health Insurance Research Initiative (CHIRI™) Issue Brief summarizes case studies of five States with separate SCHIP programs. Researchers conducted interviews with key stakeholders (e.g., SCHIP administrators, families of CSHCN) early in SCHIP implementation to determine whether CSHCN experienced problems in accessing health care in SCHIP programs with limits and/or exclusions in coverage design. Researchers found:

- Many CSHCN who were enrolled in SCHIP relied on the program as their primary source of health care coverage.
- Generally, CSHCN enrolled in SCHIP did not experience any problems in obtaining a primary health care provider or routine specialty services.
- Certain services—including physical, occupational and speech therapies, home health care, and mental health and substance abuse services—were difficult to obtain in some study States.
- Many families of CSHCN enrolled in SCHIP reported that they had to navigate a complex system of State and Federal programs in order to supplement SCHIP coverage.



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“Families of CSHCN enrolled in SCHIP were satisfied with access to primary care and routine specialty services.”

WHAT WAS LEARNED

Researchers conducted surveys of State program officials, families of CSHCN with severe chronic health conditions, advocates, and other key informants in five States (Georgia, Kansas, Pennsylvania, Utah, and Virginia) with separate SCHIP programs in 2000. These SCHIP programs were selected because they represented different regions of the country and, compared with Medicaid, imposed limits and/or exclusions on certain services or were ambiguous in defining a standard of medical necessity, among other reasons. These States were not representative of all SCHIP programs at the time of the study. Therefore, it is important not to generalize these findings to all State SCHIP programs.

Low-Income CSHCN Relied on SCHIP as Their Primary Source of Health Care Coverage

Many State SCHIP officials who were interviewed for this study believed that most CSHCN were enrolled in Medicaid. Families of CSHCN and child advocates in several of the study States reported, however, that many CSHCN enrolled in SCHIP rather than Medicaid. These CSHCN were not eligible for

State Coverage Decisions in Separate SCHIP Programs

States with separate SCHIP programs can make coverage design decisions by:

1. Deciding what services to cover in their State SCHIP Plan.
2. Setting the maximum amount of services that health plans are required to provide enrollees who need the service. The majority of States with separate SCHIP programs (26 out of 35) contract with health plans.
3. Defining how health plans determine when enrollees are entitled to services. The medical necessity standard used to make individual treatment decisions (i.e., when an individual's health condition merits access to health care services) is critical in determining whether, how often, and how much of a service is provided.

Medicaid, Supplemental Security Income (SSI), or State programs because their family income was too high or their medical conditions did not qualify them for these programs. Other CHIRI™ studies have also found that many CSHCN are enrolled in SCHIP.

Primary and Routine Specialty Care Were Readily Accessible, Yet Some Services Were Limited

SCHIP enrollees with special health care needs did not report problems in accessing a primary care provider or routine specialty care services in the study States. Overall, families of CSHCN were satisfied with the primary and routine specialty care that their child received under SCHIP. However, some families and advocates reported that it was difficult to find a participating primary care provider with expertise in serving CSHCN.

Some study States made accommodations for CSHCN when designing their SCHIP programs and benefit packages. These programs used a range of benefit and plan structures, provider requirements, and policies to address the unique needs of this population. In spite of these accommodations, families of CSHCN with severe chronic health conditions—i.e., children whose health needs were more complex or severe (e.g., spina bifida) than the typical CSHCN—experienced significant challenges in accessing certain services under SCHIP. Services that were difficult to obtain included: physical, occupational, and speech therapies; home-based health care; mental health and substance abuse services; and non-emergency transportation (e.g., transportation of a wheelchair-bound child).

SCHIP Program Design and Medical Necessity Definitions Limited Coverage for Certain Specialty Services

Some of the study States limited certain services under SCHIP. For example, one study State limited rehabilitative therapy (e.g., physical, speech, and occupational therapy) in its State SCHIP Plan. In other cases, the study States did not explicitly limit services but their coverage decisions had that effect. This typically occurred when a State did not clearly define the medical necessity standard to be used in treatment decisions in its SCHIP plan and its contract



Definition of CSHCN

CSHCN were defined as those who have or are at increased risk for a chronic, physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

with health plans, thereby permitting health plans to choose or interpret the standard. Even when States specified that plans were to provide all “medically necessary” services, ambiguous language in contracts with health plans gave them a great deal of leeway to deny services.

Although such explicit service limitations and narrow interpretations of medical necessity are common in commercial insurance policies, by Federal law, they are not allowable for children under Medicaid or in SCHIP programs that are Medicaid expansions. Medicaid’s Early and Periodic Screening, Diagnosis and Treatment (EPSDT) benefit requires that States cover any service or item that is deemed medically necessary to “correct or ameliorate defects and physical and mental illnesses and conditions, regardless of whether the service or item is covered under the State Medicaid program.”

Supplemental Services Were Difficult To Access and Limited to Very Needy Children

State and Federal programs—including the Title V Maternal and Child Health Services Block Grant Program (Title V MCH), Early Intervention (Part C of the Individuals with Disabilities Education Act), and special education programs in schools—provide services and supports that can augment SCHIP coverage. However, families and advocates reported that, depending on the program, income restrictions and/or medical condition criteria made it difficult to access these services. In addition, a number of program officials indicated that some of these programs were targeted to the neediest of children because of significant limits in funding, staffing, or other resources.

CONCLUSION

SCHIP enables States to extend health care coverage to low-income children who would otherwise be without health insurance. It is an important source of health care coverage for some children with special health care needs. CHIRI™ research in other States indicates that from 17 percent to 23 percent of SCHIP enrollees have special health care needs.

These enrollees represent a heterogeneous population with a wide range of health care needs, including some with severe and chronic illnesses.

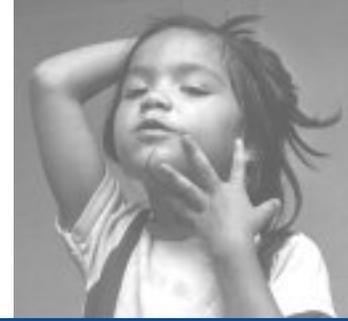
National reports indicate that the needs of CSHCN were not actively considered when policymakers initially designed SCHIP to serve a generally healthy population of children. Yet even in the early phases of SCHIP implementation, separate SCHIP programs made some program accommodations for CSHCN. In addition, these programs were effective in providing primary care and routine specialty services to enrollees with special health care needs.

Although States implemented program accommodations, families of CSHCN with severe chronic health conditions in some of the study States reported unmet needs in spite of SCHIP enrollment. A number of factors may play a role in limiting access to care for these children. One possible explanation is that these CSHCN may be expending their coverage limits under SCHIP or are being denied coverage because of narrow or ambiguous medical necessity standards.

However, challenges with health care access are not experienced only by CSHCN and are not specific to SCHIP. Enrollees in both private and public insurance programs including Medicaid may experience barriers and limited access to care even though Federal law clearly prohibits such limits under Medicaid in the case of children.

This study was conducted early in SCHIP’s implementation. Since that time, many of the study States have implemented program and policy changes that affect CSHCN. Although these findings are not generalizable to all States with separate SCHIP programs, they are instructive as to the experiences of CSHCN in accessing care in SCHIP programs with coverage limits and/or exclusions. Given fiscal constraints, public health insurance programs and other programs that serve CSHCN may be susceptible to cuts that could adversely affect this population of vulnerable children, particularly if coverage protections are not in place.

“Limits and/or exclusions in SCHIP and restrictive program eligibility requirements in other Federal and State programs created gaps in coverage for CSHCN with severe chronic health conditions in some of the study States.”



STUDY METHODOLOGY

This CHIRI™ Issue Brief is based on case studies of separate SCHIP programs in five diverse States (Georgia, Kansas, Pennsylvania, Utah, and Virginia), selected because of limits and/or exclusions in health care services considered essential to CSHCN. Other selection criteria included geographic spread, date of program implementation, estimated number of CSHCN in the State, and a minimal focus on CSHCN in SCHIP program design. Georgia and Kansas, despite being States that implemented Medicaid look-alike programs, were included because their plans imposed significant exclusions or limitations on services deemed essential by clinicians specializing in serving CSHCN. Georgia explicitly excludes “non-emergency transportation, targeted case management, services solely for persons over age 19, and some services that to be needed require a level of disability that would qualify the child for Medicaid” and subjects all other services for SCHIP enrollees to the same limitations and prior approvals that currently apply in the Georgia Medicaid plan for adults. In addition, Georgia leaves sufficient ambiguity regarding the definition of medical necessity that warranted its inclusion as a study State. Kansas, although very explicit in its plan and managed care contract about the use of a preventive definition of medical necessity in individual coverage determinations, limits coverage of rehabilitative therapy (e.g., physical, speech, and occupational therapy). This information reflects the design of SCHIP programs at the time of the study (2000). Even though changes have occurred in SCHIP design and coverage since this time, analysis of these changes was outside the scope of this study.

A list of services essential for CSHCN was developed based on a literature review and criteria recommended by nationally recognized pediatricians who provided expert guidance to this project. Researchers used the national definition of children with special health care needs from the Maternal and Child Health Bureau, Health Resources and Services Administration. Researchers analyzed the benefit packages of all States with separate SCHIP programs in 2000 to determine whether these essential services were provided, restricted, or excluded. States with separate SCHIP programs that had the greatest number of exclusions and/or limitations were

POLICY IMPLICATIONS

States seeking to strengthen or reengineer public health insurance programs for low-income children may want to consider strategies that some States are using to increase access for children with special health care needs. These strategies include the following:

- Define medical necessity broadly, such as the preventive standard used for Medicaid’s EPSDT benefit, in State SCHIP plans and contracts with health plans.
- Conduct risk assessments for all new SCHIP enrollees to determine the status of CSHCN.
- Require that health plans identify primary care providers with expertise in serving CSHCN.
- Ensure access to a medical home for CSHCN and, where appropriate, allow specialists to serve as primary care providers for CSHCN.
- Gather comprehensive data on the type and frequency of specialty services used by CSHCN to inform program decisions about benefit packages.
- Create partnerships and seamless systems of care between SCHIP and other Federal and State programs that serve CSHCN (e.g., the Title V MCH program, Early Intervention, and special education) and ensure that families of CSHCN are aware of and better able to access available services and supports.
- Offer wraparound packages of supplemental services for those CSHCN who have exceeded coverage limits or who require additional services not provided under SCHIP.
- Involve families of CSHCN in the design of SCHIP coverage and the overall system of care for CSHCN.

identified, and five case study States were selected from this sample using the selection criteria.

Interviews were conducted with State SCHIP and Medicaid officials, representatives from other key State programs (e.g., the Title V MCH program), safety net providers, consumer and advocacy groups, and families of SCHIP enrollees with special health care needs. An interview protocol was developed and tailored to each primary study audience. With the exception of families, the majority of interviews were

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Related CHIRI™ Studies

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conducted by telephone between January and June of 2002. Parents of CSHCN currently or formerly enrolled in SCHIP were interviewed in focus groups between March and November of 2002. Families of CSHCN were recruited by the local Title V MCH program or a consumer/advocacy organization, resulting in a sample of families whose children tended to have more severe chronic health conditions than the typical child with special health care needs. Families were offered a stipend of \$25 for their participation in the focus group and a \$25 reimbursement for child care and transportation expenses.

There are several limitations to this study. The study States were specifically selected based on SCHIP program design choices that limited and/or excluded services considered essential for CSHCN with no cross-comparisons to other public insurance programs. Families interviewed for the study were recruited by a local MCH or child advocacy program, which could introduce bias into reporting. Finally, the qualitative case study approach does not allow for a rigorous assessment of SCHIP impact on access to and use of services by CSHCN. Given these and other limitations, it is important to not generalize these findings to all State SCHIP programs.

SOURCES AND RELATED STUDIES OF INTEREST

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For More Information

More information on CHIRI™ projects can be found at www.ahrq.gov/chiri/. Let us know how you use CHIRI™ research findings by contacting info@ahrq.gov. Topics of future CHIRI™ Issue Briefs include:

- Premium subsidy programs: who enrolls, and how do they fare?
- The impact of SCHIP enrollment on provider participation in Medicaid.
- The role SCHIP plays in the patchwork insurance system for children.

ABOUT CHIRI™

The Child Health Insurance Research Initiative (CHIRI™) is an effort to supply policymakers with information to help them improve access to, and the quality of, health care for low-income children. Nine studies of public child health insurance programs and health care delivery systems were funded in the fall of 1999 by the Agency for Healthcare Research and Quality (AHRQ), The David and Lucile Packard Foundation, and the Health Resources and Services Administration (HRSA). These studies seek to uncover which health insurance and delivery features work best for low-income children, particularly minority children and those with special health care needs. This Issue Brief was based on research conducted by the CHIRI™ project “Responsiveness of SCHIP to Children with Special Health Care Needs” (Principal Investigator: Sara Rosenbaum, George Washington University).

CHIRI™ FUNDERS

The Agency for Healthcare Research and Quality, part of the U.S. Department of Health and Human Services, is the lead agency charged with supporting research designed to improve the quality of health care, reduce its costs, address patient safety and medical errors, and broaden access to essential services. AHRQ sponsors and conducts research that provides evidence-based information on health care outcomes; quality; and cost, use, and access.

The David and Lucile Packard Foundation is a private family foundation that provides grants in a number of program areas, including children, families and communities, population, and conservation and science.

The Health Resources and Services Administration, also part of the U.S. Department of Health and Human Services, directs national health programs that provide access to quality health care to underserved and vulnerable populations. HRSA also promotes appropriate health professions workforce supply, training, and education.

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