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RESPONSIVENESS OF SCHIP TO CHILDREN WITH SPECIAL HEALTH CARE NEEDS

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Executive Summary

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RESPONSIVENESS OF SCHIP TO CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Statement of the Problem

The State Children's Health Insurance Program (SCHIP) provides states with significant discretion to design health insurance arrangements for children. At the heart of the SCHIP statute and regulations lies a fundamental choice: whether to extend the reach of the Medicaid program to additional low-income children, or instead, to fashion an alternative, non-entitlement, separate program that may use different eligibility standards and offer benefits and delivery structures that more closely resemble those found in traditional commercial insurance plans. The decisions that states make have important implications for children, particularly the relatively small but significant group of children with chronic illnesses, disabilities and conditions who require additional types, and greater levels of, health care.

Research Objectives

The purpose of this project was to examine in detail the structure of separate SCHIP programs and the effects of state design choices on children with special health care needs, as well as on the health providers that furnish care to such children. Because separate SCHIP programs can vary enormously in eligibility, coverage, and overall program design, and because existing information on program structure is broad and limited, this project had several components, each of which was calculated to produce detailed information relevant to questions of eligibility, coverage, and overall program design.

Study Design and Methods

The study was designed to gather the type of in-depth information that is necessary to determine whether separate SCHIP programs depart from Medicaid principles, and, if so, in which dimensions (i.e., eligibility, benefits and coverage, service delivery and conditions of participation, and consumer safeguards), and to assess the potential effects of state choices on coverage for children with special health care needs. It aimed to test two main hypotheses.

First Hypothesis. States that elect to establish separate SCHIP programs will use the flexibility available under the statute to depart from Medicaid principles in a range of ways demonstrated by variability in features of program design.

This hypothesis was tested through the use of descriptive study techniques that compared against a Medicaid benchmark the eligibility, coverage and benefits, service delivery and conditions of participation, and consumer safeguards designs of separate SCHIP

programs. Specifically, these included: an in-depth descriptive study of the right to coverage under separate SCHIP programs through analysis of state enabling legislation; and a series of comparative studies of eligibility criteria, benefit coverage, and managed care design features under separate SCHIP programs through analysis of state SCHIP plans and contracts between state SCHIP agencies and managed care organizations.

Second Hypothesis. Variability in coverage and benefits such as found in separate SCHIP programs will influence access to and utilization of health care by children, including children with chronic conditions or special health care needs.

While the first set of studies considered the possible effects on children, including children with special health care needs, of state choices regarding eligibility, benefits, and managed care that are prohibited under Medicaid but possible in an insurance system, it did not directly examine whether the variability in coverage and benefits found in separate SCHIP programs actually influenced access to care by children with special health care needs. For that reason, two additional studies were conducted, which provided an improved understanding of the probable effects of the departure of separate SCHIP programs from Medicaid on coverage of children with special health care needs. These two studies included: telephone interviews with the medical directors of managed care organizations that administer both the Medicaid and SCHIP programs for the state in states with separate SCHIP programs that have issued separate contracts for Medicaid and SCHIP services in order to gain a more in-depth understanding of the coverage decisionmaking process and how it might affect access to care by children with special health care needs; and on-site and telephone interviews with key state and consumer informants in a subset of states with separate SCHIP programs to obtain further information regarding eligibility, benefits, managed care designs, and implementation issues in order to gain a more in-depth understanding of the factors underlying state choices in these areas and the actual implications of those choices for the access to care and utilization of services by children with special health care needs.

Findings

The first set of studies and the two additional studies produced the following findings on program design and implementation under SCHIP and their likely impact on children with special health care needs and their access to care.

Program design phase

States were expected to make insurance design choices along the whole spectrum of choices, from, at one end, choices that would lead their separate SCHIP program to closely mirror the Medicaid program, to, at the other end, choices that would bring their separate SCHIP program more in line with a commercial health insurance product, but a majority of states was expected to depart from Medicaid. On the one hand, were a state to select net family income to determine eligibility, adopt the full Medicaid benefit package and the Medicaid medical necessity definition, use the same delivery system as Medicaid, and create a right to SCHIP coverage and a right to appeal eligibility and

coverage decisions, then its program would be considered to be heavily “tipped” toward Medicaid. On the other hand, were a state to move away from the Medicaid benchmark, e.g., by introducing amount, duration and scope limits, excluding classes of benefits, failing to expressly adopt the Medicaid preventive medical necessity standard (either by its own choice or by delegating the power to define the term to its contractor), and/or opting against an entitlement, then its program would be considered to be “tipped” toward commercial health insurance.

Overall, the findings from these studies support the hypothesis that states, when allowed to exercise discretion in designing health insurance programs for near-poor and low-income children, will “tip” their insurance design choices in the direction of conventional insurance and away from the unique principles of the Medicaid program. More specifically, the analysis found that the 34 states with separate SCHIP programs as of Fall 2000 varied in their reference to Medicaid rules and principles, but that in all four respects—eligibility, benefits and coverage, service delivery, and consumer safeguards—their insurance design choices had the effect of moving their SCHIP programs away from the Medicaid model of delivering care to children. The majority of states imposed benefit limits and exclusions not permissible under Medicaid, opted for a narrow definition of medical necessity and allowed the use of standardized treatment guidelines in coverage decisionmaking; chose to contract with full-risk managed care organizations for services using contractual documents distinct from the Medicaid contracts creating a separate “business line” for SCHIP-covered services; and avoided the creation of a legally-enforceable right to coverage.

Program implementation phase

In order to explore the potential impact of state design choices on children with special health care needs, we selected a subgroup of 14 states, which used separate managed care contracting documents for Medicaid and SCHIP services and thus clearly signaled their intention to depart from the extensive specifications usually found in Medicaid managed care contracts and more closely follow standard commercial contracts, with the potential effect of creating two separate business lines for insurers participating in both programs. We found that insurers exercised discretion in deciding whether SCHIP-enrolled children with special health care needs would obtain coverage of services that the researchers deemed essential to these children. In general, under SCHIP, insurers would have restricted certain services most needed by children with special health care needs, such as speech and physical therapy, motorized wheelchairs, and assistive communication devices in ways not permissible under Medicaid. In addition, the less acute the condition suffered by the child, the more likely insurers would have been to impose limitations and exclusions, particularly in the coverage of speech and physical therapy and hearing aids.

We further explored the actual impact of state design choices on children with special health care needs by focusing on a subgroup of five separate SCHIP programs that used a contracting document separate from Medicaid and limited and/or excluded services that the researchers deemed essential to children with special health care needs. In general, these programs were not structured to accommodate children with special health care

needs with more severe conditions. Rather, they were designed to provide health care to large numbers of generally healthy children. Many SCHIP officials reported that children with special health care needs are not enrolled in the SCHIP program, and are instead enrolled in Medicaid through Supplemental Security Income. Other informants from Title V agencies, and from consumer and advocacy organizations, as well as parents disagreed (except in one state), reporting that many children with special health care needs do not qualify for Medicaid because they do not meet the income or disability criteria. Therefore, many children with special health care needs from low-income families have no choice but to rely on SCHIP for health insurance. Generally, informants reported having no difficulty obtaining primary health care services or seeing a specialist through their SCHIP plan. However, many respondents from nearly all informant types reported that obtaining some essential services was a significant challenge. Several SCHIP programs limit and/or exclude services essential to children with special health care needs. When these services are needed, but not available through SCHIP, children with special health care needs may only access these services through the Title V program; the early intervention program (ages 0-3); the local school system (school-aged children); or other state/locally funded program. In some cases, these programs are constrained by limited resources and cannot always serve all in need.

Recommendations

Taken together, these findings have important implications for access to care by children with special health care needs enrolled in separate SCHIP programs. First, the majority of states have used the flexibility offered them under SCHIP to scale back benefit packages and impose premiums and cost-sharing to make their public programs “look more like private insurance, and have not focused their attention on children who may require services beyond those covered in the scaled back benefit packages; rather, they have focused their attention on designing programs to provide health care to large numbers of generally healthy children. While this is not necessarily an issue for most children who are healthy and essentially require maintenance care, it can be one for children who have special needs that require services in amounts that exceed the norm. Second, preliminary evidence suggests that, under SCHIP, children with special health care needs face barriers in obtaining services considered essential to their health, and, though other programs may be available as a source of care to supplement their SCHIP benefits, they must deal with the eligibility and financial constraints imposed on these programs. As a result, many children with special health care needs stay in the basic SCHIP program with nowhere else to turn for needed care.

Although additional research is needed to measure and compare actual use of services by children with special health care needs who have Medicaid and SCHIP coverage, this study suggests that states may want to pay particular attention to children with special health care needs, by mobilizing the multiple state agencies whose mission is to serve them at the design stage to create a system where these children can be directed to the appropriate sources of care, and coordinating the delivery of services at the implementation stage to help ensure that fewer of these children fall through the cracks.

List of Products

Peer-reviewed Articles

Rosenbaum, S., Smith, B., Sonosky, C., Repasch, L., and Markus, A. (2001) Devolution of Authority and Public Health Insurance Design: National SCHIP Study Reveals an Impact on Low-Income Children. 1 *Houston Journal of Health Law & Policy* 5: 33-61.

Reports

Rosenbaum, S., and Smith, B. (2001) *State SCHIP Design and the Right to Coverage*. [Policy Brief #1] Washington, D.C.: Center for Health Services Research and Policy, Department of Health Policy, George Washington University School of Public Health and Health Services. Available at www.gwhealthpolicy.org.

Rosenbaum, S., Markus, A., Sonosky, C., and Repasch, L. (2001) *State Benefit Design Choices under SCHIP: Implications for Pediatric Health Care*. [Policy Brief #2] Washington, D.C.: Center for Health Services Research and Policy, Department of Health Policy, George Washington University School of Public Health and Health Services. Available at www.gwhealthpolicy.org.

Rosenbaum, S., Shaw, K., and Sonosky, C. (2001) *Managed Care Purchasing Under SCHIP: A Nationwide Analysis of Freestanding SCHIP Contracts*. [Policy Brief #3] Washington, D.C.: Center for Health Services Research and Policy, Department of Health Policy, George Washington University School of Public Health and Health Services. Available at www.gwhealthpolicy.org.

Rosenbaum, S., Markus, A. (2002) *State Eligibility Rules under Separate State SCHIP Programs—Implications for Children's Access to Health Care*. [Policy Brief #4]. Washington, D.C.: Center for Health Services Research and Policy, Department of Health Policy, George Washington University School of Public Health and Health Services. Available at www.gwhealthpolicy.org.

Rosenbaum, S., Sonosky, C., Shaw, K., and Mauery, D.R. (2002) *Behavioral Health and Managed Care Contracting under SCHIP*. [Policy Brief #5]. Washington, D.C.: Center for Health Services Research and Policy, Department of Health Policy, George Washington University School of Public Health and Health Services. Available at www.gwhealthpolicy.org.

Panel Presentations

Rosenbaum, S. “Early Results from the Child Health Insurance Research Initiative (CHIRI): Studies of State Experiences with SCHIP” 2002 Annual Research Meeting. Academy for Health Services Research and Health Policy. Washington, D.C.: June 24, 2002.

Markus, A. “State Insurance Design Choices under Separately-Administered SCHIP Programs: Implications for Pediatric Health Care” 130th Annual Meeting. American Public Health Association. Philadelphia, PA: November 11, 2002.

Poster Presentations

Rosenbaum, S., Markus, A., Sonosky, C. “State Insurance Design Choices under Separately-Administered SCHIP Programs: Implications for Pediatric Health Care.” 7th Annual GWU Health Sciences Research Day Program. The George Washington University Medical Center. Washington, D.C.: April 19, 2002.

Rosenbaum, S., Markus, A., Sonosky, C. “State Insurance Design Choices under Separately-Administered SCHIP Programs: Implications for Pediatric Health Care.” 2002 Annual Research Meeting. Academy for Health Services Research and Health Policy. Washington, D.C.: June 23, 2002.

Markus, A., Rosenbaum, S., Joseph, J., Stein, R., Shaw, K., Meyer, A. “Insurers’ Coverage Decisionmaking of Selected Services for Children with Special Needs Enrolled in Separate SCHIP Programs.” 8th Annual GWU Health Sciences Research Day Program. The George Washington University Medical Center. Washington, D.C.: April 25, 2003.

Nolan, L., Harvey, J., Vaquerano, L. “The Impact of Separately Administered SCHIP Programs on Children with Special Health Care Needs.” 2003 Annual Research Meeting. Academy for Health Services Research and Health Policy. Nashville, TN: June 27, 2003.

Forthcoming Products

Rosenbaum, S., Budetti, P. Low-Income Children and Health Insurance: Old News and New Realities. Forthcoming in *ePediatrics Supplement*.

Nolan, L., Harvey, J., Vaquerano, L. *The Impact of Separately Administered SCHIP Programs on Children with Special Health Care Needs [DRAFT TITLE]*. [Forthcoming]

Markus, A., Rosenbaum, S., Joseph, J., Stein, R., Shaw, K., Meyer, A. *MCO Coverage Decisionmaking of Selected Services for Children with Special Health Care Needs under Separate SCHIP Programs [DRAFT TITLE]*. [Forthcoming]

Rosenbaum, S., Markus, A., Sonosky, C. *State Insurance Design Choices under Separately-Administered SCHIP Programs—Synthesis of Findings [DRAFT TITLE]*. [Forthcoming]

I. Introduction

A. Nature of the Research Problem

The State Children's Health Insurance Program (SCHIP) provides states with significant discretion to design health insurance arrangements for children. At the heart of the SCHIP statute and regulations lies a fundamental choice: whether to extend the reach of the Medicaid program to additional low-income children, or instead, to fashion an alternative, non-entitlement, separate program that may use different eligibility standards and offer benefits and delivery structures that more closely resemble those found in traditional commercial insurance plans. The decisions that states make have important implications for children, particularly the relatively small but significant group of children with chronic illnesses, disabilities and conditions who require additional types, and greater levels of, health care.

B. Purpose, scope and methods of the investigation

The Center for Health Services Research and Policy (CHSRP) of the George Washington University School of Public Health and Health Services carried out a three year project to examine the implications of how states structure their separate SCHIP programs for children's access generally and for children with special health care needs in particular. The overall focus of study was the group of 34 states that, as of Fall 2000, had approval from the Centers for Medicare and Medicaid Services (CMS) to establish a separate SCHIP program for some or all targeted low-income children. The research design was intended to carry out two basic tasks that are essential to understanding the policy significance of the 1997 SCHIP legislation. First, the study was designed to gather the type of in-depth information that is necessary to understand whether separate SCHIP programs in fact depart from Medicaid principles at all and, if so, in which dimensions (i.e., eligibility, entitlement and other consumer safeguards, benefits and coverage, managed care delivery system and conditions of participation for managed care organizations). Through the use of descriptive techniques that compare against a Medicaid benchmark the eligibility, benefit, and managed care design of separate SCHIP programs, the study sought to test the hypothesis that states that elect to establish separate SCHIP programs will use the flexibility available under the statute to depart from Medicaid principles in a range of ways and will reflect high variability in program design. Second, the study was designed to explore the potential effects of state design choices on coverage for children with special health care needs. Through the use of telephone interviews and case studies, the study sought to test the hypothesis that state design choices will influence access to and utilization of health care by children, particularly children with special health care needs.

C. Nature of the findings

Overall, the findings from this study support the two hypotheses used to guide the research. First, the majority of states used the flexibility offered them under SCHIP to scale back benefit packages and impose premiums and cost-sharing to make their public

programs “look more like private insurance.” Generally, they have not focused their attention on children who may require services beyond those covered in the scaled back benefit packages; rather, they have focused their attention on designing programs to provide health care to large numbers of generally healthy children. Second, preliminary evidence suggests that, under SCHIP, children with special health care needs face barriers in obtaining services considered essential to their health, and, though other programs may be available as a source of care to supplement their SCHIP benefits, they must deal with the eligibility and financial constraints imposed on these programs. As a result, many of these children will stay in the basic SCHIP program with nowhere else to turn for needed care.

II. Review of the Literature

A. In general

The State Children's Health Insurance Program (SCHIP) was enacted in 1997 in order to allow states to extend additional, publicly-subsidized coverage to near-poor children who are otherwise ineligible for coverage, including existing state Medicaid arrangements. States may use their federal SCHIP allocations to either expand Medicaid, develop alternative programs that have the features of traditional insurance coverage, or combine the two approaches.¹ The SCHIP legislation was a product of a series of policy and political compromises that, among other matters, reflected a desire on the part of a number of state to extend coverage to near-poor children through arrangements that more closely resembled traditional insurance rather than Medicaid.²

SCHIP implementation generated numerous structural and policy choices for states. It also presented policymakers with a central, long-term, multi-faceted research question: what are the implications of a state's choice to implement SCHIP as a Medicaid expansion versus a program modeled on more traditional insurance principles, both for children generally and for children with special health care needs particularly? It is the latter group of children for whom Medicaid's "non-insurance" features have been potentially the most significant and whose experiences in a more traditional form of insurance coverage are of heightened interest.

B. In particular

While Medicaid typically is equated with insurance for purposes of coverage analyses, in fact it is profoundly different. Medicaid is the third party financing that operates on principles distinct from insurance. Medicaid's main purpose is to cover families and individuals who, because of disability, age, extreme poverty and dependence, exist outside of the employment system. Insurance, on the other hand, was designed for workers and their families; it was designed to spread the risk of routine health problems facing working age Americans and their families and thus is built to avoid risk selection.³

In four basic respects, Medicaid differs from commercial insurance. First, Medicaid offers coverage that is far broader than that found in traditional commercial insurance plans. Medicaid covers defined classes of benefits that typically are excluded from commercial coverage. Examples include home care services, personal attendants, and other services for the treatment and management of chronic illness and disability.

Second, Medicaid prohibits coverage limitations and exclusions, as well as coverage restrictions that are unrelated to medical necessity but that often are found in commercial insurance. For example, commercial insurance may prohibit coverage of speech therapy for children whose need is based on a health "condition," such as a developmental disability, while permitting coverage for an adult recovering from an illness or injury, such as a stroke^{4,5,6} The latter needs are seen as falling within traditional insurance norms

because they relate to events from which recovery to normalcy might be expected. The former needs relate to a chronic condition from which no recovery to normalcy is possible and thus lies outside of the purview of insurance.⁷

Third, as a function of special coverage rules applicable only to children, Medicaid requires the application of a preventive standard of care to determinations of medical necessity. Services must be covered if they are needed to promote growth and development, not merely if they are needed to treat illness or injury, as is the case with insurance coverage. This special pediatric coverage standard is unique to Medicaid.⁸

Fourth, Medicaid prohibits all cost-sharing in the case of pediatric care. Coverage is thus first-dollar and comprehensive. Determinations can be related only to the need for benefits that treat conditions and that aid in growth and development; coverage cannot be denied on the basis that the care is educational or for a condition.

Thus, normal limitations that typically are built into insurance arrangements, such as cost-sharing, limited benefit classes, coverage exclusions and limitations in the areas of chronic illness and disability and conditions, and the use of a “restore normal functioning” standard of medical necessity are prohibited under Medicaid in the case of children.

States that elect to offer separate SCHIP programs can choose a very different approach to benefits and coverage structure than that which is possible under Medicaid. Programs may limit coverage to that offered by commercial insurers, using one of several different insurance “benchmarks.”⁹ Federal coverage standards under SCHIP thus essentially employ a “defined contribution” rather than “defined benefit” approach. Because commercial benchmarks are permissible, so are commercially utilized limitations and exclusions, as well as commercial definitions of medical necessity. Subject to certain federal limits, states also may use cost-sharing in their separate programs.^{10, 11}

Beyond its radically different coverage structure, Medicaid imposes standards on eligibility that do not apply in separate SCHIP programs. Medicaid is a legal entitlement. Thus, all eligible children must be assisted.¹² Separate SCHIP programs can limit enrollment through the use of budget caps. Medicaid eligibility must be extended to all children who satisfy financial eligibility standards as well as other criteria related to legal status and residency. Families whose incomes exceed eligibility cutoffs receive deductions for child care, earned income, and additional shelter costs; in most states, families also can deduct from income incurred expenses for out-of-pocket health costs that reduce available income. Separate SCHIP programs, on the other hand, may elect to calculate eligibility on the basis of gross family income, to avoid the use of deductions and disregards, and to build in other eligibility criteria that would not be permitted in Medicaid, such as waiting periods, age limits, and residential or geographic targeting. While the use of preexisting condition exclusions is prohibited,¹³ the statute does not prohibit separate programs from using “proxy” targets whose effect may be the exclusion of children with severe physical or mental health conditions or disabilities (e.g.,

covering only children who do not also receive care financed through state Title V programs for children with special health care needs).

States that elect to develop their SCHIP plans as separate programs rather than Medicaid expansions also have a potentially important area of flexibility not available to state Medicaid agencies. Federal Medicaid law contains numerous conditions of participation applicable to states that use managed care systems for their enrollees as well as managed care organizations that sell services to Medicaid agencies. These minimum requirements include requirements related to access and network sufficiency for both primary and specialty care, benefit disclosure requirements, and the use of grievance and appeals procedures, as well as procedures that ensure continued coverage for Medicaid benefits while a benefit dispute is being resolved. This latter requirement is particularly significant in the case of children with special health care needs who are undergoing a course of treatment that may be interrupted by a plan's coverage and treatment decisions. The SCHIP legislation is silent on standards for managed care. As a result, states may elect to either adhere to Medicaid principles or apply different criteria and standards for access, network, coverage decisionmaking, and grievances and appeals.

In light of these fundamental differences, a state's decision to establish a separate program or expand Medicaid possibly takes on great meaning for children. In the case of all children, the decision to establish a program that permits the denial of coverage to eligible individuals for budgetary reasons would have meaning in the event that resource limitations arise as a factor. Furthermore, in the case of children, cost-sharing has been shown to affect both the probability of health care utilization, as well as the amount of services used.¹⁴ Regardless of health status, children eligible for a separate SCHIP program could possibly be affected by both enrollment limits and cost-sharing requirements. Similarly, all children could potentially be affected by the performance standards adopted for participating managed care organizations.

Equally as significant but more subtle, perhaps, are the potential implications for children with special health care needs that arise from eligibility, benefit, and other structural design choices that are made in the case of separate SCHIP programs. A challenge that has confronted health services researchers in this area is the lack of a single definition of children with special health care needs. A review of population definitions and eligibility criteria for existing state programs for children with special health care needs (Title V), special education and early intervention programs, and the Supplemental Security Income program eligibility criteria yielded three generic definitional approaches: 1) definitions based on the presence of a chronic condition; 2) definitions based on the presence of a functional impairment, and 3) definitions based on the presence of an elevated service need.¹⁵ Perrin *et al.* suggest that the condition-specific or "categorical" approach is neither pragmatically nor conceptually sound.¹⁶ Westbrook and colleagues studied a large national dataset to test how prevalence estimates and characteristics of children vary by the way that disability is defined. They caution that "the implications of using different definitions and definitional components on both the prevalence and the characteristics of children with disabilities need to be considered before data can be applied responsibly and appropriately."¹⁷

A consensus panel convened by the federal Bureau of Maternal and Child Health has recommended a definition largely based on elevated service need, i.e., “children with special health care needs are 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.” Newacheck operationalized that definition using the 1994 National Health Interview Survey on Disability.¹⁸ The distinguishing feature—elevated service needs—of this population of children with chronic illness and disabilities potentially brings into even sharper relief the differences between Medicaid and commercial insurance coverage.

The discussion above sets forth the basis for our hypotheses that state separate SCHIP programs may be structured in ways that are significantly different from Medicaid and that these differences have implications for all children generally and for special needs children in particular. These differences, if evident, have significant implications for public policy. SCHIP represented an effort to depart from longstanding Medicaid policy regarding eligibility and coverage of children. As the implementation of separate SCHIP programs has proceeded, numerous states have begun to question the continued wisdom of retaining Medicaid as a model of pediatric coverage at all because of the constraints it places on state design choices and because of perceptions regarding family preferences for non-Medicaid coverage.

Before making long-term decisions regarding whether or not public pediatric coverage policy should shift toward a traditional commercial model and away from Medicaid principles, policy makers need more detailed understanding regarding the implications of such a shift. For example, shifting to an income eligibility test that eliminates the more complex income evaluation standards used in Medicaid may dramatically simplify the program and ease enrollment. At the same time, the use of a simple gross income test may in fact create an “eligibility cliff” that excludes many families whose children might otherwise qualify for coverage were certain adjustments made to family income. This question is particularly important for special needs children, whose families may appear to have “excess” income but who in fact face extraordinary medical care costs.

Even more significant perhaps, are the implications for children of moving away from Medicaid coverage principles. The effects may be limited for children whose health care needs fall within normal pediatric ranges (although even modest cost-sharing has been shown to reduce utilization of care among children generally). However, the importance of this policy decision grows as children’s health needs become more complex. Because these children represent a small subset of the entire pediatric population, their experiences under different forms of coverage can easily be overlooked.

The demographic and socioeconomic and health characteristics of children with special needs have been studied. Newacheck has looked at several dimensions of access to care for children with and without existing special health care needs.¹⁹ He found that most children with existing special health care needs had a usual source of care in 1994 and most (88.8 percent) had health insurance as well. Looking at utilization, he found

that children with existing special health care needs had more than twice as many physician contacts and five times as many hospital days as other children.

There is, of course, considerable evidence that uninsured children receive less care than insured children, and that differences become more pronounced as health needs grow.^{20, 21} However, the issue of how access to and use of care differs for special needs children under different forms of insurance coverage has received relatively little research attention. The small amount of evidence that does exist suggests that the breadth and depth of Medicaid may in fact make a difference.

A study by Rosenbach,²² published in 1989, was designed to evaluate the determinants of physician utilization by low-income children (both those on Medicaid, 46 percent, and those privately-insured, 38 percent) based on 1980 NMES data for children in families with incomes less than 150 percent FPL). Rosenbach found that Medicaid children were more likely than either privately-insured or uninsured children to visit an office-based physician. Rosenbach found that “privately-insured low-income children had a lower probability of visiting an office-based physician than Medicaid children; however, among those with at least one office visit, there was no difference. She also speculated that “low-income children covered by private health insurance may have lower use of office-based physicians’ services, in part, because of the limited scope of benefits covered by their policies.” In the NMES data base used by Rosenbach, privately-insured children had much narrower benefits for ambulatory care than for inpatient care. While SCHIP coverage may be far deeper than that examined by Rosenbach, in other respects, coverage may be as narrow as that which the NMES discovered. Similarly, while the prevalence of cost-sharing in pre-SCHIP commercial plans examined by Rosenbach may have been greater than that permitted under SCHIP, the evidence regarding low-income children’s sensitivity to cost-sharing suggests that financial obligations do not have to be substantial before their effects on low-income children are felt.²³

A 1987 study by Butler *et al.* looked at health insurance coverage and physician use among children with disabilities (operationalized as children receiving special education).²⁴ He found that there were wide variations in the scope of insurance payment for care, such that parents of publicly-insured children paid out-of-pocket for only five percent of all physician visits as compared to 30 percent of visits for the privately-insured. Even for children with various low-prevalence disabilities, when privately-insured, parents paid out-of-pocket for 23 percent of all physician visits.” Again, these findings may or may not be somewhat dated due to the increased penetration of managed care.

Thus, while there may be some evidence of a differential effect on access to and utilization of health care by low-income children depending on whether they receive health insurance coverage through a public program (Medicaid) or private insurance, the issue requires further research using more timely information. Yet it is this issue that lies at the heart of the debate over Medicaid expansion versus separate SCHIP. And because of their higher utilization of services and limitations in the normal daily activities of

childhood, this issue takes on even greater relevance for children with special health care needs.

C. Preliminary studies

This study builds on previous research conducted by the Center for Health Services Research and Policy (CHSRP) in the area of Medicaid eligibility, coverage, and managed care^{25,26, 27,28, 29}

Work by CHSRP and numerous other research efforts document the unique aspects of Medicaid eligibility and the use of complex standards for determining eligibility, including conditions of eligibility and the application of eligibility criteria to family income. Taken together these studies suggest that many families with incomes that at first blush appears to exceed program eligibility standards in fact are eligible for benefits once adjustments for the cost of living and medical care costs are taken into account. It is therefore possible to recognize the potential policy significance of permitting states to depart from these prior standards in fashioning the eligibility component of their freestanding programs.

CHSRP is also nationally known for its research into Medicaid coverage policies generally and the nature and structure of Medicaid managed care arrangements, particularly those systems that utilize contracts with comprehensive managed care organizations. CHSRP conducts an annual, point-in-time study of Medicaid managed care contracts using actual contract documents collected from all states offering comprehensive arrangements with companies that offer managed care plans modeled on commercial insurance principles.³⁰ From this ongoing study, it is evident that a typical Medicaid managed care contract more closely resembles commercial insurance in that it offers a narrower spectrum of benefits than that covered by Medicaid. It is common to find that contracts limit the number of certain types of benefits and services (e.g., a preset number of mental health encounters or the use of drug formularies more restricted than that used by Medicaid). It is also common for states to permit their contractors to apply limitations that do not apply to the Medicaid program itself and to use alternative definitions of medical necessity.

In the case of Medicaid, states effectively supplement their managed care products with additional services and benefits. Separate SCHIP programs may take the same approach (i.e., buying limited coverage from private companies and supplementing this coverage with expanded “wrap-around” benefits). However, unlike Medicaid, separate programs are free to limit coverage and benefits to commercial levels.

The Medicaid managed care contract study also shows that state Medicaid agencies devote considerable attention to issues of network composition and capabilities and service delivery and also require the use of extensive grievance and appeals procedures. Separate SCHIP programs may elect to utilize similar, detailed specifications. On the other hand, agencies may create simpler contracts, relying instead on the discretion of their contractors to build systems similar to those offered to their private purchasers.

III. Study Design and Methods

A. Study design

This study was designed to include several distinct, but intertwined, components, all of which aimed at testing two central hypotheses related to SCHIP program design and its implications for children's access to care.

First Hypothesis. States that elect to establish separate SCHIP programs will use the flexibility available under the statute to depart from Medicaid principles in a range of ways demonstrated by variability in features of program design.

This hypothesis was tested through the use of descriptive study techniques that compared against a Medicaid benchmark the eligibility, coverage and benefits, service delivery and conditions of participation, and consumer safeguards designs of separate SCHIP programs. Specifically, these included: an in-depth descriptive study of the right to coverage under separate SCHIP programs through analysis of state enabling legislation; and a series of comparative studies of eligibility criteria, benefit coverage, and managed care design features under separate SCHIP programs through analysis of state SCHIP plans and contracts between state SCHIP agencies and managed care organizations.

Second Hypothesis. Variability in coverage and benefits such as found in separate SCHIP programs will influence access to and utilization of health care by children, including children with chronic conditions or special health care needs.

While the first set of studies considered the possible effects on children, including children with special health care needs, of state choices regarding eligibility, benefits, and managed care that are prohibited under Medicaid but possible in an insurance system, it did not directly examine whether the variability in coverage and benefits found in separate SCHIP programs actually influenced access to care by children with special health care needs. For that reason, two additional studies were conducted, which provided an improved understanding of the probable effects of the departure of separate SCHIP programs from Medicaid on coverage of children with special health care needs. These two studies included: telephone interviews with the medical directors of managed care organizations that administer both the Medicaid and SCHIP programs in states with separate SCHIP programs that have issued separate contracts for Medicaid and SCHIP services in order to gain a more in-depth understanding of the coverage decisionmaking process and how it might affect access to care by children with special health care needs; and on-site and telephone interviews with key state and consumer informants in a subset of states with separate SCHIP programs to obtain further information regarding eligibility, benefits, managed care designs, and implementation issues in order to gain a more in-depth understanding of the factors underlying state choices in these areas and the actual implications of these choices for the access to care and utilization of services by children with special health care needs.

B. Population studied

For all four components, the population studied was the 34 states with approved and implemented separate SCHIP programs as of Fall 2000 (Table 1). However, for each component, the number of states studied varied depending on the specific focus of the study.

Table 1
State SCHIP Administration: Medicaid Expansion versus Separate SCHIP Programs
(as of Fall 2000)

State	Medicaid Expansion	Separate SCHIP Program (in Whole or in Part)	Maximum Medicaid Income Eligibility Limit ⁰ /Upper SCHIP Income Eligibility Limit in Separate SCHIP Programs (% FPL)		Number of Children Served Under Separate SCHIP Program (FY 2000)
AL	✓	✓	133/133/100/100	200	37,587
AK	✓				
AZ		✓	140/133/100/50	200	60,803
AR	✓				
CA	✓	✓	200/133/100/100	250	428,641
CO		✓	133/133/100/43	185	34,889
CT	✓	✓	185/185/185/185	300	9,593
DE		✓	185/133/100/100	200	4,474
DC	✓				
FL	✓	✓	200/133/100/100	200	201,409
GA		✓	185/133/100/100	235	120,626
HI	✓				
ID	✓				
IL	✓	✓	200/133/133/133	185	17,659
IN	✓	✓	150/150/150/150	200	6,534 ¹
IA	✓	✓	200/133/133/133	200	8,699
KS		✓	150/133/100/100	200	26,306
KY	✓	✓	185/150/150/150	200	14,477
LA	✓				
ME	✓	✓	200/150/150/150	200	8,828
MD ²	✓	✓	200/200/200/200	300	N/A
MA	✓	✓	200/150/150/150	200 (400+) ³	40,128
MI	✓	✓	185/150/150/150	200	21,231
MN	✓				
MS	✓	✓	185/133/100/100	200	8,295
MO	✓				
MT		✓	133/133/100/71	150	8,317
NE	✓				
NV		✓	133/133/100/89	200	15,946
NH	✓	✓	300/185/185/185	300	4,119
NJ	✓	✓	185/133/133/133	350	50,361
NM	✓				
NY	✓	✓	185/133/100/100	192 ⁴	764,147
NC		✓	185/133/100/100	200	103,567
ND	✓	✓	133/133/100/100	140	2,267

State	Medicaid Expansion	Separate SCHIP Program (in Whole or in Part)	Maximum Medicaid Income Eligibility Limit ⁰ /Upper SCHIP Income Eligibility Limit in Separate SCHIP Programs (% FPL)		Number of Children Served Under Separate SCHIP Program (FY 2000)
OH	✓				
OK	✓				
OR		✓	133/133/100/100	170	37,092
PA		✓	185/133/100/71	200 (235) ⁵	119,710
RI	✓				
SC	✓				
SD	✓	✓	140/140/140/140	200	299
TN	✓				
TX	✓	✓	185/133/100/100	200	84,974
UT		✓	133/133/100/100	200	25,294
VT		✓	225/225/225/225	300	4,081
VA		✓	133/133/100/100	185	37,681
WA		✓	200/200/200/200	250	2,616
WV		✓	150/150/100/100	200	21,659
WI	✓				
WY		✓	133/133/100/67	133	2,547
Total	35	35			2,334,866

SOURCES: Centers for Medicare and Medicaid Services. (2000) State Children's Health Insurance Program (SCHIP) Aggregate Enrollment Statistics for the 50 States and the District of Columbia for Federal Fiscal Year (FFY) 2000. Accessed at www.hcfa.gov; Ross, D.C., and Cox, L. (2000) Making it Simple: Medicaid for Children and CHIP Income Eligibility Guidelines and Enrollment Procedures-Findings from a 50-State Survey Washington, D.C.: Center on Budget and Policy Priorities. Prepared for the Kaiser Commission on Medicaid and the Uninsured.

NOTES:

⁰ Medicaid income eligibility guidelines for infants (0-1)/children (1-5)/children (6-16)/children (17-19).

¹ The Indiana State SCHIP Annual Report for FY 2000 states that "there were 6,534 children who obtained health insurance through Indiana's State-designed program at some point between January 1, 2000 (the beginning of the program) and September 30, 2000."

² Maryland received approval on November 7, 2000 for a state plan amendment to implement a separate child health program effective July 1, 2001.

³ Massachusetts provides state-financed coverage to children with incomes above SCHIP levels. Eligibility is shown in parenthesis.

⁴ New York has a net income standard of 192 percent of the FPL.

⁵ Pennsylvania provides state-financed coverage to children with incomes above SCHIP levels. Eligibility is shown in parenthesis.

The first component, the in-depth descriptive study of the right to coverage under separate SCHIP programs, analyzed the state enabling legislation enacted in 33 of the 34 states with separate SCHIP programs (in the 34th state, the expansion was authorized under the state's existing Section 1115 waiver).

The second component, the series of comparative studies of eligibility criteria, benefit coverage, and managed care design features under separate SCHIP programs, analyzed the 34 state SCHIP plans and the 26 standard contracts between state SCHIP agencies and managed care organizations.

The third component, the telephone interviews with the medical directors of managed care organizations that administer both the Medicaid and SCHIP programs, focused on the 14 states with separate SCHIP programs that have issued separate contracts for Medicaid and SCHIP services.

The fourth and final component, the on-site and telephone interviews with key state and consumer informants, focused on five states with separate SCHIP programs that have issued separate contracts for Medicaid and SCHIP services and that limit and/or exclude services essential to children with special health care needs.

C. Sample selection

The sample selection varied across study components depending on their specific objective.

For the in-depth descriptive study of the right to coverage under separate SCHIP programs, the main sample selection criteria were that states had to have a separate SCHIP program and a state SCHIP enabling statute. This led to the inclusion of 33 of the 34 states with separate SCHIP programs as study states.

For the series of comparative studies of eligibility criteria, benefit coverage, and managed care design features under separate SCHIP programs, the main sample selection criteria were that states had to have a separate SCHIP plan implemented as of Fall 2000, and use managed care contracts. This led to the inclusion of all 34 states with separate SCHIP programs.

For the telephone interviews with the medical directors of managed care organizations that administer both the Medicaid and SCHIP programs, the main sample selection criteria were that states had to have a separate SCHIP program, use managed care contracts that are separate from Medicaid, and contract with managed care organizations participating both in Medicaid and SCHIP. This led to the inclusion of 14 of the 34 states with separate SCHIP programs and a total of 71 medical directors employed by Medicaid and SCHIP managed care organizations.

For the on-site and telephone interviews with key state and consumer informants, the main sample selection criteria were that states had to have a separate SCHIP program, use managed care contracts that are separate from Medicaid, limit and/or exclude services essential to children with special health care needs, and represent different regions of the country. This led to the inclusion of five of the 34 states with separate SCHIP programs and a total of 81 informants (state officials, safety net providers, advocates, health plans and families).

D. Instruments used

The instruments used varied across study components depending on their objective but all were newly developed and tested to answer the specific questions at hand.

For the in-depth descriptive study of the right to coverage under separate SCHIP programs and the series of comparative studies of eligibility criteria, benefit coverage, and managed care design features under separate SCHIP programs, researchers collected and analyzed 34 separately-administered state SCHIP plans in effect during 2000, as well as 33 state statutes creating separate SCHIP programs, using a review instrument that captured four key elements of insurance design: (1) consumer safeguards, including the right to coverage; (2) eligibility standards and methodologies; (3) benefits and coverage; and (4) service delivery. Researchers complemented their analysis with 14 managed care contracts that were separate from the state’s Medicaid agreement with managed care organizations, three primary care case management contracts, and 12 Medicaid managed care contracts. The review of these state documents was structured to categorize state plan and contract design to reflect certain critical distinctions between Medicaid and SCHIP (Table 2).

Table 2. Key Areas of Insurance Design and Identified Issues

Key area of insurance design	Identified Issues
Eligibility	Whether state SCHIP plans used a gross or a net income test (as Medicaid does), whether the plans used the same definition of “family” as Medicaid, and whether they attributed as available to the child the income of the household, i.e., the income of the parents or spouses plus that of individuals other than the parents or spouses, or the income of family, i.e., the income of the parents or spouses only (as Medicaid does) to determine a child’s eligibility for their separate SCHIP programs.
Benefits and coverage	Whether state SCHIP plans listed all classes of benefits, including vision, dental and hearing care, covered under federal Medicaid law, and whether the documents specified amount, duration and scope limitations that would not be applicable in Medicaid; whether the plans and/or the contracts defined the medical necessity standard used in separate programs to calibrate benefit limitations and to make individual decisions regarding whether covered services would be furnished to an enrolled child.
Service delivery	Whether state SCHIP plans opted for full-risk managed care organizations rather than other forms of managed care to deliver services to SCHIP-covered children and whether SCHIP delivery systems interacted with Medicaid managed care delivery systems.
Consumer safeguards	Whether the state SCHIP legislation explicitly or implicitly created an entitlement, or explicitly or implicitly rejected an entitlement; whether the state SCHIP plans and/or contracts provided for an external appeals process in addition to the managed care organizations’ own internal appeals process.

Source: CHSRP, 2002.

For the coverage decisionmaking study and the implementation case studies, interview protocols were developed and used as guides for the interviews.

The research questions developed for the coverage decisionmaking study focused on whether the medical director would cover without limitations, restrictions or review, would not cover, or would cover with limitations, restrictions or review a list of 13 services that were recommended as medically necessary by the treating physician of two hypothetical children with special health care needs (one with spina bifida, the other with head trauma). For the purpose of this study, similar hypothetical children covered by Medicaid were assumed to receive all of the services listed in these two scenarios since they were considered medically necessary. The services were chosen based on the findings from the first set of studies which showed that separate SCHIP programs tend to limit services, such as physical, occupational and speech therapy, which children with special health care needs most likely would need. These services were grouped into five broad categories of benefits (Table 3).

Table 3. Category of Benefit and Type of Service Included in the Survey

Category of benefit	Type of service
Prescription drugs	1. medications for the treatment of an acute ear infection 2. medications for the treatment of seizures 3. medications for the prevention of spasticity
Speech and physical therapy	4. speech and language evaluation 5. speech therapy 6. physical therapy to limit the development of contractures in the lower extremities
Durable medical equipment	7. hearing aids 8. wheelchair specially fitted to child's size and capabilities 9. motorized wheelchair 10. assistive communication devices, such as computers with speech capacity 11. pump for overnight feedings
Enabling transportation	12. transportation to medical appointments for wheelchair-bound child
Case management/care coordination	13. a case manager to coordinate the child's care

Source: CHSRP, 2002.

The research questions developed for the implementation case studies focused on how a particular SCHIP model was selected and implemented in the state and how families and consumers experienced seeking care within the implemented program. An interview protocol was developed to answer these two central questions and tailored to each audience included in the study resulting in six separate documents: a consumer advocacy group interview protocol, a consumer focus group interview protocol, an individual consumer interview protocol, a safety net provider interview protocol, a SCHIP health plan representative interview protocol, and a state official and policymaker interview protocol. Four research questions provided the analytic framework for conducting the research and data analysis (Table 4).

Table 4. Main Research Questions and Sub-questions

Main research questions	Main research sub-questions
Selection and implementation process of a particular SCHIP program design	<ol style="list-style-type: none"> 1) Has the SCHIP program been structured to accommodate children with special health care needs 2) What services essential to children with special health care needs are available/excluded from the SCHIP program?
Families and consumers' experiences with the implemented program	<ol style="list-style-type: none"> 1) What is the ability of children with special health care needs to seek/obtain health care services through the SCHIP program? 2) What impact has SCHIP had on children with special health care needs?

Source: CHSRP, 2002.

E. Statistical techniques employed

No statistical techniques were employed.

III. Presentation of Findings

A. In-depth descriptive study of the right to coverage under separate SCHIP programs.

Do states in their enabling legislation establishing separate SCHIP programs confer upon eligible children an individual legal right to health insurance benefits (i.e., an individual entitlement) under *state* law, similar to the entitlement that Medicaid eligible children enjoy under federal law? The question of whether states guarantee necessary health coverage for low-income children through the creation of an individual entitlement is fundamental to the study of state policy making under SCHIP.

Our in-depth descriptive study of the right to coverage under separate SCHIP programs found that:

- Among the 34 separate SCHIP programs, none created an individual entitlement to SCHIP coverage as a matter of state law. This finding probably is not surprising. Were a state to entitle children to coverage on an open-ended financing basis, one would expect the state to adopt a simple Medicaid expansion. Even if a state wanted to extend to near-poor children a more limited Medicaid benefit package or employ greater cost-sharing requirements, the more practical financing approach might be an expansion of Medicaid and an accompanying proposal to DHHS to alter benefit and cost-sharing rules for the expansion population, as several states have done under §1115 of the Social Security Act (for example, Massachusetts, Minnesota, Tennessee, and Oregon).
- Among the 34 states with separate SCHIP programs, 33 enacted separate legislation that can be analyzed (in the 34th state, expansions were authorized by the state under its existing §1115 demonstration program). Of these 33 states, nine laws appear to mandate expenditures for eligible children up to fixed, authorized funding levels. Some of these state laws authorize spending and enrollment up to the level of combined state and federal appropriations. Alternatively, some states express an intent to cover as many children as possible or anticipate enrollment up to the level of appropriations. This spending mandate could support a legal interpretation under traditional judicial principles that the legislation creates a restricted right to coverage among eligible children to receive coverage, but only as long as specified appropriations are available. Furthermore, none of these nine state laws prohibits an individual action to enforce the right to coverage. Therefore, in these states, it might be possible for courts to infer the existence of an individually enforceable right under state law, depending on the judicial policy of a state regarding the ability to privately enforce rights even in the absence of an express right of action.
- In the remaining 24 states, the enabling legislation authorizing the state's program either expressly or by implication does not provide any legal right to coverage. Two-thirds of the laws (16 states) explicitly state that nothing in state law should be deemed to create an entitlement; the remaining one-third (eight states) use legislative language that is so broadly drafted that under standard judicial principles, the

legislative language used probably would not support a claim of a right to coverage, either through an individual entitlement or a restricted right to coverage, even where the state has funds available for coverage.

The findings from this study are important in understanding state policy choices and priorities in the context of health coverage for low-income children. They suggest that when given the option, states tend to avoid the creation of a legally enforceable right in the case of pediatric health coverage. Even where, as in the enactment of SCHIP, Congress indicates a willingness to support the continued guaranteed right to coverage among children by giving states an option to use their SCHIP funds to do so, most states elected an alternative to the traditional Medicaid approach of open-ended entitlement. Furthermore, only a minority of states with separate SCHIP programs appear willing to authorize spending on children under what could be characterized as a capped entitlement, thereby guaranteeing eligible children a right to coverage up to authorized spending levels. Most states with separate programs appear to have retained discretionary control over the actual level of expenditures they might be required to undertake during a year, regardless of authorized state funding levels or the fact that the federal government has guaranteed a specified financial allotment to the states. In these states enrollment could be frozen legally, despite the fact that funds remain available for coverage of eligible children.

If low-income children are to be guaranteed health coverage as a matter of law, this study indicates that such an entitlement necessarily would arise from the existence of a mandatory federal individual entitlement rather than from separate state decisions to entitle low-income children to coverage as a matter of state law.

B. Series of comparative studies of eligibility criteria, benefit coverage, and managed care design features under separate SCHIP programs

Eligibility criteria

How is financial eligibility for SCHIP actually calculated, that is, what are the formulas developed by states to count children's family income for purposes of measuring eligibility? This question is of central importance to overall program administration because of the federal legal prohibition against assistance to targeted low-income children who are in fact Medicaid-eligible. This prohibition on duplication of assistance was a crucial assumption in the enactment of SCHIP. It is also key to the conservation of limited SCHIP funding for targeted low-income children who are ineligible for either Medicaid or any other form of health insurance, particularly as unemployment rises and the number of lower income children without health insurance may be poised to increase. Because Medicaid and SCHIP are both means-tested programs, financial eligibility turns in great part on a child's income eligibility. A basic tenet of Medicaid since its enactment (and one that is thus incorporated into SCHIP because of how the two statutes are linked) is that income eligibility is determined by how much countable income a child is considered to have, not on the family's gross income. Medicaid establishes federal standards for how income is evaluated and counted. SCHIP, on the other hand, leaves these standards to state discretion, imposing in their place what can be thought of as an "outcome" test, namely, that SCHIP funds be used for children who are not eligible for Medicaid.

Our review of the financial eligibility criteria reported by separate SCHIP programs in their state plans found that:

- The majority of states with separate SCHIP plans did not lay out clear rules in their plans that allowed us to determine whether they followed Medicaid financial eligibility rules or departed from them. More specifically, only 13 states—Illinois, Indiana, Kansas, Massachusetts, Maine, Mississippi, North Carolina, North Dakota, New Hampshire, Utah, Vermont, Virginia and West Virginia—provided sufficient information in their plan on how they would adjust gross income, define family, and attribute income. The remaining 21 states were unclear in their plan on one standard, two standards or all three standards. Among the 21 states whose plans were ambiguous or lacked clarity, income attribution was the area where the majority of states did not specify which rules they would use, whereas income valuation was the area least frequently omitted. In addition, the majority of state plans lacking clarity were more often unclear on two of the three income standards rather than on only one or all three standards studied.
- Only 20 of the 34 states with separate SCHIP programs in effect in 2000 report using rules to count income that are sufficiently compatible to Medicaid rules on countable income so that a determination of SCHIP eligibility simultaneously could be reasonably interpreted as a finding of ineligibility for Medicaid. Of those 20 states, only 12 state SCHIP programs unequivocally pick up where Medicaid rules leave off in their valuation of countable income. In the remaining eight states, the income standards and methodologies “tip” toward Medicaid in two of the three areas of income determination. While Michigan “tips” toward Medicaid in the areas of income valuation and attribution, the remaining seven states—Arizona, Colorado, Connecticut, Delaware, Illinois, Montana, and Wyoming—“tip” toward Medicaid in the areas of income valuation and family definition.
- In the remaining 14 states, the financial eligibility standards and methodologies for evaluating income (i.e., the rules for counting income) are either more restrictive than those used under Medicaid (Florida) or else are sufficiently ambiguous so that it is impossible to know without a detailed audit if more restrictive criteria in fact are in use (Alabama, California, Georgia, Iowa, Kentucky, New Jersey, New York, Nevada, Oregon, Pennsylvania, South Dakota, Texas, and Washington). In these states, despite the fact that the SCHIP income eligibility standard may be nominally higher for SCHIP than it is for Medicaid (e.g., 200 percent of the federal poverty level versus 150 percent of the federal poverty level), the formulas used to count income and thus calculate eligibility may be more restrictive than those used under Medicaid. As a result, a SCHIP child’s countable income in these states actually may be lower than it is for a Medicaid-enrolled child. State income valuation rules appear to be more restrictive in several basic areas, in particular, in the availability of deductions against income, rules used to calculate family size, and the rules that determine exactly what household income will be counted toward a child when considering eligibility (i.e., income attribution).

These findings support several basic conclusions. First, the use of more restrictive standards under SCHIP, while not expressly prohibited, would appear to be inconsistent with the program's central purpose, namely, to assist certain low-income children whose family resources place them beyond the limits of their state's Medicaid program. Second, using countable income rules that are more restrictive than those applicable in Medicaid means that in these states, SCHIP has a greater potential to allocate limited program resources to children who do not qualify for assistance because they are in fact eligible for Medicaid. This mis-allocation means that other low-income children who truly do not meet Medicaid standards may find that no assistance is available; indeed, states where SCHIP expenditures are projected to exceed their annual allotments are expected to consider queuing targeted low-income children for assistance because of funding shortages and some states, such as North Carolina, already have begun to do so. Third, the use of more restrictive standards and methodologies under SCHIP also means that the resulting benefit packages available to enrolled children may be thinner in order to accommodate additional children and cost-sharing may be higher. To the extent that more limited benefits and higher cost-sharing have been predicated on these families' greater ability to afford out-of-pocket payments, the fact that the countable income standards actually are more restrictive would appear to undercut the basic logic underlying more limited benefits.

In states that use more restrictive SCHIP financial eligibility criteria, there would appear to be a need for an additional post-eligibility determination enrollment procedure designed to avert erroneous enrollment into SCHIP of children who in fact may be poorer than their Medicaid counterparts. Because the use of an additional post-eligibility determination enrollment procedure could further delay the receipt of necessary care, states using more restrictive standards may wish to revise their SCHIP standards and methodologies to make them compatible with Medicaid.

Benefit coverage

To what extent do state agencies adopt conventional insurance norms or adhere to special principles of Medicaid coverage design for children in designing separate SCHIP programs? The question of coverage design is particularly relevant for children with low prevalence conditions and special health care needs. Increasingly, conventional insurance uses standardized coverage norms to limit coverage and treatment. These standardized norms take the form of across-the-board treatments and exclusions, limited definitions of medical necessity, and the use of irrefutable, standardized treatment guidelines in determining when covered treatments will be available. All of these practices are impermissible under Medicaid, which uses exceptionally broad preventive standards to determine coverage of children; such standards favor coverage of children with low prevalence problems. The issue of coverage design takes on particular significance in the context of the current health system, since the use of managed care (which dominates separate SCHIP programs, as it does Medicaid) effectively merges issues of coverage, treatment, and ultimately, the quality of health care.

Our detailed, nationwide analysis of coverage design choices by separate SCHIP plans, as well as managed care contracts maintained by separate programs, indicates that in terms of exclusions, coverage limitations and the definition of medical necessity itself, virtually all states with separate SCHIP programs "tip" their programs to parallel

conventional insurance and depart from special Medicaid coverage rules. Specific findings include:

- Among the 34 states with separate SCHIP programs in effect in 2000, 32 states use coverage exclusions that would not be permissible in Medicaid in the coverage of medical treatment services. Services that tend to be excluded entirely are hospice services, case management services, enabling services, including non-emergency transportation, care coordination, home and community-based services, long-term inpatient rehabilitation services, and private duty nursing services. All states use coverage limitations in addition to those permitted under Medicaid in the coverage of medical treatment services. Certain services commonly used by children with developmental and mental disabilities appear to be more likely to contain exclusions and limitations than others. This is particularly true in the case of outpatient mental health services, physical and occupational therapy, and speech therapy. In the case of vision, dental and hearing care, far fewer states entirely exclude any one of these classes of services. Dental care and audiology services are two classes of service that are equally excluded. While total exclusions are less common, coverage limitations are extremely common. All states limit these services to some degree. Typical examples of service limitations related to vision, dental and hearing include coverage of dental services for the treatment of injury only or up to a certain dollar amount (e.g., \$600 or \$1,000 per year).
- Of the 19 states that provide a definition of medical necessity as a stated part of their program design, 13 states use a definition that parallels the preventive standard of medical necessity used by the Medicaid program. This standard ensures that coverage is available when needed to promote growth and development. The definitions existing in the other six states take a more conventional insurance approach, limiting coverage to treatment for illnesses and injuries and eschewing any notion of treatment to attain functioning, maintain functional status, or avert the deterioration of functioning. Of note, among the 18 contracts with a definition, the preventive definition was present more often in contracts integrated with Medicaid (eight states) than in separate contracts (five states), and the more limited definition was present more often in separate contracts (four states) than in contracts integrated with Medicaid (one state). The remaining 15 states do not build any definition into their state program coverage design. Of those, eight contract with managed care organizations, six pay directly for services, and one uses primary care case management. Since the majority of these states contract with managed care organizations, this finding suggests that these states elect instead to delegate the authority to define medical necessity to contractors, which would be consistent with a state's desire to use its SCHIP flexibility to foster conventional insurance design principles rather than the unique standards employed by Medicaid.
- None of the 26 standard contracts used by separate SCHIP programs in their purchase of managed care products prohibits the use of standardized treatment guidelines in determining when covered treatment will be available, a practice that would not be permitted under Medicaid. A state's silence on this practice, which is an emerging

custom and practice under conventional insurance, would likely be construed as sanctioning the practice, particularly in those states in which the basic design of the state SCHIP program is premium support: that is, where the state appears to intend to use its SCHIP allocations to replicate conventional insurance for low-income uninsured children rather than to extend the special coverage afforded by Medicaid.

These findings suggest that, when given the option to do so, states will adopt conventional insurance norms in lieu of Medicaid's special coverage rules for children, at least with respect to children who are near-poor. Whether this distinction on states' part between near-poor children and the poorest children is justified is debatable, since only a nominal amount of family income separates the two groups, and health status data show virtually no distinction in health status measures for the poorest children and their near-poor counterparts.

How state choices affect the accessibility and quality of health care for children with chronic illness and disability is unclear. In states that supplement SCHIP benefits with other sources of health care funding for disabled children (e.g., Title V), the effects may be minimal. In states without complementary programs that are closely coordinated with basic SCHIP benefits to overcome the limits of SCHIP, the impact of exclusions, limitations, a narrowed definition of medical necessity, and the use of standardized treatment guidelines may be more significant for children with serious and chronic physical and mental disabilities.

Managed care

How do states structure and administer insurance programs for low-income children when they elect to administer separate SCHIP plans that exist outside of the requirements and constraints of Medicaid? More specifically, how do separate SCHIP programs structure "freestanding" SCHIP managed care contracts, i.e., contracts that exist independently of a state's Medicaid managed care agreements? Like Medicaid, federal law permits separate SCHIP programs to administer their programs either in accordance with traditional fee-for-service principles or as managed care systems. In addition, like Medicaid programs, SCHIP agencies that buy managed care products must do so through contracts that adhere to federal and state contract and procurement requirements. These contracts also set forth the purchaser's expectations regarding coverage, service delivery, networks, enrollment and disenrollment, and other categories of specifications. In developing their contracts, separate SCHIP agencies have two basic choices. Where the SCHIP plan's coverage and service rules are close to those used by Medicaid, the agency theoretically could adapt the state Medicaid contract to its needs through modifications and addenda. Alternatively, a separate SCHIP agency may decide to develop a freestanding purchasing agreement that is completely independent of the Medicaid contract. Where the Medicaid and SCHIP agencies operate their managed care systems under two separate contracts, important similarities and distinctions can be expected in the area of coverage, given the underlying nature of the two laws. Furthermore, distinctions may exist in the area of service delivery, service access, networks, and the interaction between contractors and the larger health systems in which they operate.

Because independently operating SCHIP contracts used by separate SCHIP programs offer insight into how states approach purchasing arrangements when freed from Medicaid's coverage and administration requirements, we sought to examine these agreements more closely.

- Of the 34 states with separate SCHIP programs, 26 states made some use of managed care purchasing arrangements, the majority through full-risk managed care-style contracts, and in a few instances through primary care case management contracts or a combination of the two. Among states buying full-risk managed care, 12 states did so through the use of contract instruments that were SCHIP-adapted. That is, the state had modified or adapted its Medicaid agreement to its SCHIP market through additional provisions. In these states, the product differentiation contained in the modifications and addenda tended to focus on coverage. Those Medicaid contract specifications related to health care access, enrollment, network structure, performance measurement, and other non-coverage factors, were generally not altered in the addenda or modification. Put another way, in these 12 states, the SCHIP purchasing instrument was a modified Medicaid agreement, with the modifications aimed principally at coverage. In the other 14 states, separate SCHIP agencies developed a freestanding contract for their SCHIP contractors; these contracts contain not only separate coverage terms but also potentially different terms related to access, networks, and other matters related to the actual performance of health care.
- The 14 freestanding SCHIP contract differ from their states' Medicaid contracts significantly with respect to the terms of coverage. For example, only 12 of the contracts explicitly specify coverage of immunization services. Federal SCHIP regulations require state plan coverage of immunizations at the levels recommended by the Advisory Committee on Immunization Practices (ACIP), an advisory arm to the Centers for Disease Control and Prevention (CDC). Presumably therefore, in all states with freestanding contracts, ACIP vaccines would be a state plan benefit. However, to the extent that this level of coverage is not made an explicit part of the contract, residual obligations could accrue to the SCHIP agency. Similar variations in state approaches to coverage and the degree of discretion accorded contractors can be seen in other services, such as vision, dental, and hearing care. While all states specify vision and dental services, only three specify screening for elevated blood lead levels, only 12 identify developmental assessments as a basic part of the preventive exam, and only nine specify adherence to the Guidelines for Health Supervision established by the American Academy of Pediatrics. These guidelines have for decades been incorporated into federal guidance related to the preventive pediatric component of Medicaid, the Early and Periodic Screening, Diagnostic and Treatment services (EPSDT) benefit. In the case of medical treatment services, e.g., hospital inpatient and outpatient care, laboratory and diagnostic services, physician services, prescribed drugs, and treatments for behavioral disorders, all contracts require at least some level of coverage. However, not all of the contracts require coverage of certain therapies, services and equipment used by children with more complex physical health needs. Fewer than half of all states specify coverage of

medical case management services as the term is defined in Medicaid (i.e., assistance in obtaining access to necessary medical, educational, social and other services).

- While the 14 freestanding SCHIP contracts differ from their states' Medicaid contracts significantly with respect to the terms of coverage, they also differ in other important ways. The freestanding SCHIP contracts are less likely to specify access and network performance standards, but at the same time are virtually as likely to specify cultural competence in the manner of health care.

Variation in coverage between Medicaid and SCHIP managed care contracts should be expected. SCHIP was enacted in large part as a means of accommodating state concerns that the prescriptive nature of Medicaid in the areas of entitlement and coverage was inhibiting expansions of coverage to millions of low-income and uninsured children. Thus, one would expect that the insurance agreements executed by separate SCHIP programs would offer more limited benefits, more narrow standards of medical necessity, and more extensive coverage exclusions (and a more limited likelihood of residual coverage through the SCHIP plan). At the same time, because the target population reached through separate SCHIP programs are very low-income children whose coverage is a Medicaid option, it is striking that so many freestanding SCHIP contracts define service delivery and access obligations differently. Were enrollees the only consideration, the differences between SCHIP and Medicaid contracts would be difficult to understand, since there is no obvious reason why a Medicaid, but not a SCHIP, contractor should be expected to coordinate its coverage and care activities with a school clinic, for example. But our previous comparisons of Medicaid managed care and employer-sponsored plans suggest that state Medicaid agencies take a more expansive view than other group purchasers of their role in shaping the health delivery systems they buy for members. To the extent that the goal of SCHIP is to compensate low-income children for their lack of access to employer-sponsored coverage (rather than their lack of Medicaid coverage), then one would expect SCHIP agencies to follow employer-sponsored contracts rather than the more detailed terms of Medicaid agreements.

Even if employer sponsored plans, rather than Medicaid, serve as the model for freestanding SCHIP contracts, the issue of coordination between systems of care is a pressing one. Extensive provider resistance to Medicaid participation is a longstanding problem. This resistance also eliminates as a practical solution to the problem of continuity a condition of participation requirement of dual participation in both programs. States and managed care organizations could be expected to resist any effort to condition participation in one program on participation in both.

C. Coverage decisionmaking study (telephone interviews with the medical directors of managed care organizations that administer both the Medicaid and SCHIP programs for the state)

How do insurers that administer both the Medicaid and SCHIP programs make coverage decisions for SCHIP-covered children who have special needs? Are there any differences between the benefits mandated under SCHIP and the implemented benefits as illustrated by insurers' coverage decisions? What is the potential impact of these

decisions for children's access to care? In telephone interviews conducted between March and June 2002, researchers presented medical directors with two patient scenarios of hypothetical children with special needs (one with spina bifida, the other with head trauma) and asked them to make a coverage decision for each of the services listed, which were identical for both scenarios. The main coverage decision outcomes were: the insurer would have provided the service without restriction, limit or review; the insurer might have provided the service, but only with some limit, restriction or special review; the insurer would not have provided the service. Where appropriate, respondents also provided the likely basis for their decision. The response rate was 13 percent (after repeated invitations to participate in the study), with a representation of less than half of the selected states.

We found variations in coverage decision outcomes among insurers depending on the type of coverage, category of benefit, acuity of the children's medical condition, and state of residence.

- Certain services most needed by children with special needs, such as speech and physical therapy, motorized wheelchairs, and assistive communication devices, were generally restricted under SCHIP by both states and insurers in ways not permissible under Medicaid. In this study, we assumed that Medicaid-covered children presenting the same medical conditions as our two hypothetical SCHIP-covered children would obtain coverage of all of the services listed since the children's treating physicians would have recommended them as medically necessary. This is because the Medicaid program must, by law, reimburse a treatment recommended by a physician as medically necessary for a child regardless of whether it is explicitly listed as a covered benefit under the program. Under this assumption, 100 percent of the insurers would have paid for services for these two hypothetical children had they had Medicaid coverage. This is consistent with existing studies, which suggest that, although Medicaid agencies sometimes vary in their coverage decisionmaking regarding treatment for children with serious conditions, they are generally more likely to approve covered treatments than are insurers.
- Insurers were far from being in agreement on any specific service, with the exception of the coverage of a case manager to coordinate the care of the child with the more acute condition (head trauma) where 100 percent of the interviewees agreed they would cover it without any limitations. In addition, 56-78 percent of insurers would have covered medications without any limitations, when all states cover them with limits, 56-67 percent of insurers would have covered hearing aids, pumps for overnight feeding, and fitted wheelchairs without any limitations, when all states cover durable medical equipment with limits, 55 percent of insurers would cover enabling transportation without limits, when all but one state exclude enabling transportation, and 89-100 percent of insurers would have covered a case manager to coordinate care without limits, when two states exclude it and three states cover it with limits. This would imply that managed care organizations may provide, perhaps routinely, extra-contractual services by overriding otherwise applicable limits in the

case of higher needs children, even though the premium they receive is not calibrated to tolerate this type of practice.

- The less acute the condition suffered by the child, the more likely the imposed limitations and exclusions, particularly in the coverage of speech and physical therapy, and hearing aids. However, the child with the more acute condition still faced significant limitations and exclusions as well. Insurers indicated they would have been more likely to refuse coverage of speech therapy and physical therapy for the child with the less acute condition (spina bifida) because these therapies would not have been restorative. However, the majority of insurers would still have limited coverage of these therapies for the child with the more acute condition (head trauma), based on the terms of their SCHIP contract. Similarly, they would have been more likely to exclude hearing aids for the child with the less acute condition, but a few would also have excluded coverage of these devices for the child with the more acute condition.
- In the majority of cases, most insurers would have provided more generous coverage than required in the state plan and contract. However, in a few notable cases, there was a discrepancy between some insurers' decisions and the requirements of the state plan and managed care contract, with insurers excluding services when these services arguably should have been covered, albeit with some limits, according to the plan and the contract language. This was the case for speech therapy, hearing aids and assistive communication devices for the treatment of the less acute condition (spina bifida), and hearing aids and assistive communication devices for the treatment of the more acute condition (head trauma). While in one state, the language leaves little doubt that coverage should have been provided in these cases—it stipulates that the services should be covered when medically necessary and it provides a definition of medical necessity that follows the Medicaid pediatric preventive standard of medical necessity, in the remaining three states, the language leaves some ambiguity that can be left to interpretation. In the first of these three states, the plan and contract language requires coverage of speech therapy and assistive communication devices but is silent on the definition of medical necessity, thereby granting insurers the discretion to decide whether speech therapy and assistive communication devices would be medically necessary to treat a child with spina bifida and whether assistive communication devices would be medically necessary to treat a child with head trauma. In the same state, where coverage of hearing aids for the child with spina bifida came up as an issue, the plan language indicates that hearing aids should be covered whereas the contract does not, but again neither one specifies a medical necessity definition. Though the plan would appear to be freed of any liability for this specific service, it would appear that the state may have some residual liability. In the second of these three states, the plan and contract language requires coverage of assistive communication devices but is silent on the definition of medical necessity, thereby granting insurers the discretion to decide whether assistive communication devices would be medically necessary to treat both children, whether they suffer from spina bifida or from head trauma. In the third of these three states, coverage of speech therapy to treat the child with spina bifida and coverage of

hearing aids to treat both cases (spina bifida and head trauma) were at issue. While both the plan and the contract state that these services should be covered to treat an impairment due to a congenital birth defect (speech therapy) or should be excluded except to treat an impairment due to a congenital birth defect (hearing aids), they also are silent on a medical necessity definition. Although the language appears to make it clear that the services should be covered for the treatment of spina bifida, the lack of medical necessity definition leaves some residual uncertainty as to their coverage, particularly for the treatment of head trauma.

While SCHIP extends coverage to previously uninsured children with special needs, the benefits offered by state programs vary greatly and tend to be less comprehensive than those covered under Medicaid. Since, under SCHIP, “what you see is what you get,” coverage at current levels may not be sufficient to care for children with special needs. This study of mandated versus implemented benefits suggests that in most cases, insurers provide more generous coverage than required in the state plan and contract, when in fact the payment they receive does not account for these extra-contractual services. In a few notable cases, however, discrepancy arises between some of the insurers’ decisions and the plan and contract requirements, with insurers limiting or excluding services when arguably they should have been covered. In the majority of these cases, the state documents were ambiguous on which standard of medical necessity should apply, thereby leaving insurers with the discretion to apply their own, which more likely than not follows the more restrictive standard of the commercial market. Because insurers make these medical necessity decisions, the availability of external reviews of insurers’ coverage decisions becomes an important component of SCHIP program design. Our review of state SCHIP plans indicate that, while the majority of states require an internal right to appeal benefit denials, only about a third of the state plans describe an external right to appeal benefit denials, either to an independent board or a state agency. Of those, only two states explicitly provide for a right to a fair hearing similar to Medicaid and one state specifically excludes it. In addition, the limitations of the SCHIP benefit package compounded by potential, further denials by insurers make the availability of other sources of care (e.g., Title V) all the more important. Finally, additional research is needed to measure and compare actual use of services by children with special needs who have Medicaid and SCHIP coverage.

D. Implementation case studies (on-site and telephone interviews with key state and consumer informants)

Our findings suggest that separate SCHIP programs do not meet the needs of children with special health care needs with the most complex medical conditions. SCHIP programs in our study states impose limits and exclusions on services essential to the care of children with special health care needs. In some cases, children with special health care needs who exhaust those limits can access services through a complicated patchwork of agencies and service providers (e.g., Title V, school districts, other state-programs, private non-profit and faith-based organizations). However, many of these providers have their own income and medical eligibility criteria which limit children’s ability to access their services. When children with special health care needs do qualify for these

services, they often find that, due to strict limits on agency resources and funding, they may be unable to access all necessary services. Additionally, some parents are unaware of the many non-SCHIP funded resources available for their children with special needs, and therefore their children forego additional services. This is especially prevalent where SCHIP plans do not provide case management/care coordination. These findings are discussed in more detail below:

Most case study SCHIP programs were designed to cover generally healthy children. In general, the SCHIP programs in our study states were not structured to accommodate children with special health care needs with more severe conditions. Rather, they were designed to provide health care to large numbers of generally healthy children. For example, Pennsylvania's SCHIP program is modeled after a private insurance product and is provided through commercial health maintenance organizations. Utah and Virginia's programs are based on the state employee benefit package. Kansas's program is a Medicaid look-alike that uses the EPSDT benefit package in addition to using the employee benefit program as a benchmark. Georgia's program is a primary care case management model that closely resembles the state's Medicaid benefit package.

Most SCHIP health plans could not provide data on the number of children with special health care needs enrolled in their plans. Because SCHIP plans provide in-house case management services to few enrollees, they estimate that few enrollees must have serious health conditions. Some SCHIP plans have special programs targeted at children with special health care needs with less severe conditions like asthma and diabetes.

Many low-income children with special health care needs rely on SCHIP for coverage since they do not qualify for Supplemental Security Income or Medicaid. We found that in several of our study states, many children with special health care needs do not qualify for Supplemental Security Income (SSI), Medicaid or other state-only programs due to criteria based on income or medical condition. Therefore, such low-income children have no other alternative than to rely on SCHIP for medical coverage. In nearly all states, SCHIP officials reported that children with special health care needs are not enrolled in the SCHIP program, and are instead enrolled in SSI Medicaid. However, a wide range of informants including those from Title V agencies, consumer and advocacy organizations, and parents disagreed reporting that many children with special health care needs do not qualify for Medicaid either because they do not meet the income or disability criteria. The only exception was in Pennsylvania where a state-funded program allows children who meet the state disability criteria to enroll in SSI Medicaid by disregarding their parents' income. Therefore, most children with serious medical conditions are enrolled in Medicaid in Pennsylvania; however, low-income children with less severe special conditions, such as asthma and diabetes, are likely to only qualify for SCHIP.

Some states have structured their SCHIP programs to accommodate some of the needs of children with special health care needs. In some cases, Utah often waives the three month waiting period for children with serious medical conditions who are covered by COBRA. The state also requires all SCHIP plans to conduct a health risk assessment

of all SCHIP enrollees to determine which children may have special health care needs. Utah's SCHIP plans are also expected to assure that networks include primary care physicians (PCPs) with experience serving children with special health care needs, and allow specialists to serve as PCPs. Georgia's program is based on its Medicaid program and therefore includes accommodations, such as allowing specialists to serve as PCPs, and granting extensions on service limits for children with special health care needs. Because Kansas's program includes an EPSDT equivalent, SCHIP enrollees must receive all medically necessary services, whether or not such services are explicitly covered by the SCHIP program. Health plans in Kansas are expected to provide such services under the capitation they receive from the state. The SCHIP programs in Pennsylvania and Virginia resemble private insurance programs and do not include any special accommodations for children with special health care needs.

Generally, children with special health care needs have no difficulty obtaining a primary care provider or accessing primary and routine specialty health care services. We found that SCHIP enrollees with special health care needs have no difficulty finding a primary care provider (PCP), accessing primary care and some specialty services. SCHIP health plans in Kansas, Pennsylvania, Utah, and Virginia used existing commercial or Medicaid provider panels, and therefore it is generally easy to locate a doctor. Families were generally happy with the primary and specialty care they received for their children's routine needs. Some parents of children with special health care needs and advocate informants reported that it was difficult to find PCPs who had an expertise in serving children with special needs. We found that geography and general provider shortfalls posed the only significant difficulty in finding a physician or accessing services. Families did complain about the shortfall in dentists willing to participate in the SCHIP program, but this is a complaint widely shared by many families enrolled in managed care and public services, and is not specific to children with special health care needs.

SCHIP plans limit or exclude essential services for children with special health care needs. Many respondents from nearly all informant types reported that obtaining some essential services was a significant challenge. SCHIP programs in all our study states limit and/or exclude services essential to children with special health care needs. Parents and advocates reported that the most significant limits or exclusions applied to physical, occupational and/or speech therapies, home health care, mental health/substance abuse services, and non-emergency transportation. In most cases, case management/care coordination is not a covered service but is provided, to a varying degree, by many health plans in our study states out of general operating funds.

Children with special health care needs rely on a complicated patchwork of service providers and funding streams for some essential services not covered by SCHIP. When eligible, some SCHIP enrollees may obtain health care services not covered by SCHIP through a variety of providers and organizations. These include Title V programs, early intervention programs for those under the age of three, Head Start, and school districts. Eligibility for these services/programs often depends upon meeting income and/or medical condition criteria. We found that some SCHIP plans provide limited case

management/care coordination to children with special health care needs, and coordinate health plan services and care delivered by these providers. Case management is not a covered SCHIP service in Georgia, Pennsylvania, Virginia, or Utah. However, some health plans do provide this service under the administrative operating funds they receive from the state. Utah requires that all SCHIP plans provide this service even though it is not a billable service; health plans in Kansas also coordinate services with other agency providers and organizations for their SCHIP enrollees. This is not the case in Pennsylvania and Virginia, where enrollees are expected to take responsibility for their health care and coordinate their own service needs. In Georgia, primary care providers are expected to provide case management to SCHIP enrollees. However, parents rely heavily on the Title V program to provide this service.

Parents of children with special health care needs often lack information about care coordination and available resources. Many parents reported that they were unaware of various resources available to their children outside of their SCHIP health plan or local Title V provider. Many parents reported that they only learned about the Title V provider or other resources through friends, support groups, etc. Many who had had contact with Title V agencies or the Early Intervention Program (EIP) could not recall how they began receiving those services, or from which agency they were provided. This suggests that some children with special health care needs enrolled in SCHIP health plans without case management/care coordination programs may not obtain the full cadre of needed services.

Significant resource shortages for non-SCHIP providers may require children with special health care needs to forego needed services. When specific services are needed, but limited or excluded by a state's SCHIP program, children with special health care needs may access these services through agencies and providers, such as the Title V program or school districts. However, we found that these providers in all the study states face significant resource limits (i.e., personnel and funding) and often cannot afford to provide all needed services to all children with special health care needs. In some of our study states, Title V agencies have been deemed the provider of last resort and can only be accessed when all other alternatives have been exhausted. Some Title V informants reported that they must ration the care they deliver, prioritizing based on those most in need and those who have the least access to care. Therefore, children with special health care needs, who rely on Title V and other providers for services not covered under their SCHIP plans, may find that they cannot receive needed services.

Ultimately, children with special health care needs in need of certain essential services must look outside of their SCHIP plans, and navigate a complicated patchwork of other agencies and programs to obtain services (or forego them completely). Nearly all informants reported that SCHIP has had a positive impact on children with special health care needs who would otherwise be uninsured and have little access to general health care services. However, most respondents from all informant categories reported that our study states' SCHIP programs do not provide children with special health care needs with services essential to treating their special needs.

V. Discussion of Findings

A. Conclusions to be drawn from findings

Overall, the first set of findings from this study supports the hypothesis that states, when allowed to exercise discretion in designing health insurance programs for near-poor and low-income children, will “tip” their insurance design choices in the direction of commercial insurance and away from the unique principles of the Medicaid program.

More specifically, the analysis found that states with separate SCHIP programs varied in their reference to Medicaid rules and principles, but that in all four respects—eligibility, benefits and coverage, service delivery, and consumer safeguards—their insurance design choices had the effect of moving their SCHIP programs away from the Medicaid model of delivering care to children.

First, the majority of states with separate SCHIP programs used eligibility standards that were sufficiently ambiguous that it was impossible to know without a detailed audit if in fact they unequivocally picked up where Medicaid rules leave off in their valuation of countable income or were more restrictive than those used in Medicaid.

Second, the majority of states imposed benefit limits and exclusions not permissible under Medicaid, opted for a narrow definition of medical necessity, and allowed the use of fixed and irrefutable treatment guidelines in coverage decisionmaking.

Third, the majority of states chose to contract with full-risk managed care organizations for services and made managed care enrollment for SCHIP-eligible children with special health care needs a mandatory element of program eligibility. The majority of states also used contractual documents distinct from the Medicaid contracts, eschewing the need to customize contractual requirements while creating a separate “business line” for SCHIP-covered services. With respect to contract performance measures, the performance specification evaluation showed only limited obligations related to the management of children whose health needs related to their chronic conditions exceed the limits of contractual coverage, with very limited extra-contractual treatment support obligations.

Finally, the majority of states avoided the creation of a legally-enforceable right to coverage.

Similarly, the second set of findings from the coverage decisionmaking study and the implementation case studies support the hypothesis that the variability in coverage and benefits such as found in separate SCHIP programs influences access to and utilization of health care by children, including children with chronic conditions or special health care needs.

More specifically, we found that insurers exercised discretion in deciding whether SCHIP-enrolled children with special health care needs would obtain coverage of

services that the researchers deemed essential to these children. In general, under SCHIP, insurers would have restricted certain services most needed by children with special health care needs, such as speech and physical therapy, motorized wheelchairs, and assistive communication devices in ways not permissible under Medicaid. In addition, the less acute the condition suffered by the child, the more likely insurers would have been to impose limitations and exclusions, particularly in the coverage of speech and physical therapy, and hearing aids.

Furthermore, we found that separate SCHIP programs were not structured to accommodate children with special health care needs with more severe conditions. Rather they were designed to provide health care to large numbers of generally healthy children. Many SCHIP officials reported that children with special health care needs are not enrolled in the SCHIP program, and are instead enrolled in Medicaid through Supplemental Security Income. Other informants from Title V agencies, and from consumer and advocacy organizations, as well as parents disagreed (except in one state), reporting that many children with special health care needs do not qualify for Medicaid because they do not meet the income or disability criteria. Therefore, many children with special health care needs from low-income families have no choice but to rely on SCHIP for health insurance. Generally, informants reported having no difficulty obtaining primary health care services or seeing a specialist through their SCHIP plan. However, many respondents from nearly all informant types reported that obtaining some essential services was a significant challenge. Several SCHIP programs limit and/or exclude services essential to children with special health care needs. When these services are needed, but not available through SCHIP, children with special health care needs may only access these services through the Title V program; the early intervention program (ages 0-3); the local school system (school-aged children); or other state/locally funded program. In some cases, these programs are constrained by limited resources and cannot always serve all in need.

Taken together, these findings suggest that, at least in the case of near-poor children, state flexibility translates into simplified eligibility rules and more normative insurance principles that emphasize standard coverage rules and de-emphasize the unique coverage principles of Medicaid for children. They also suggest that this departure from Medicaid can have an impact of access to care for children generally and children with special health care needs specifically.

B. Explanations of limitations or possible distortion of findings

This study has several limitations. Both the in-depth descriptive study of the right to coverage under separate SCHIP programs and the series of comparative studies of eligibility criteria, benefit coverage, and managed care design features were based on the analysis of documents—state enabling statutes, state plans, and managed care contracts. Documents can be incomplete or lacking in detail, which can distort the researchers’ understanding of how a program is actually structured unless an audit or interview is conducted with the state to gain a better understanding of program design in the areas of uncertainty. Although certain areas remained unclear, various interpretations were

provided as possible state choices in those areas, including the implications of these choices. In addition, all of these documents were structured to follow applicable federal and state requirements and were legally binding and thus were assumed to provide a fair representation of a state's intent in a given area of study.

The coverage decisionmaking study also has several limitations that require caution in interpreting the results. First, the sample of states is not a representative sample, and thus findings are not generalizable to all states with separate SCHIP programs. Although the findings may not be generalizable, they provide important insights for the future of the Medicaid and SCHIP programs, as more states can be expected to move toward a commercial insurance model for the provision of services to children. Second, the number of responses from the interviews is very small, raising issues of response bias and problems of analyzability. Even with the small number of responses, however, some patterns were detectable and, as such, were interpreted as indicative of the larger picture. Third, the cases presented to the medical directors for a coverage decision described hypothetical cases of children with special needs. While this is obviously different from real-life cases, the scenarios aimed at representing realistic situations and capturing dilemmas encountered in the real world.

Similarly, the implementation case studies have a number of limitations. Like the coverage decisionmaking study, findings are not generalizable to all states with separate SCHIP programs, but because the sample states represent the extreme design choices under a flexible federal scheme they provide important lessons for all states as they seek to reengineer their public insurance programs for low-income children. In addition, the qualitative case study approach does not allow for a rigorous assessment of the impact of SCHIP on access to and use of services by children with special health care needs, although it does describe experiences that appear to indicate that such an impact exists.

C. Comparison with findings of other studies

Because SCHIP is still a program in its infancy, research in this area is still relatively scant and preliminary. While a number of other studies have examined similar issues about SCHIP program design and implementation as this study, none were structured to answer the two hypotheses developed for the study, which were specifically tied to the ongoing policy debate on the restructuring of public insurance programs for low-income children and thus expected to produce policy-relevant findings. This study is also one of the few studies which is nationwide in scope and systematically compares SCHIP with Medicaid.

Existing studies have used various quantitative and qualitative research methods and focused on various aspects of SCHIP. Earlier studies have examined various aspects of the SCHIP eligibility issue, but they have not specifically focused on the specific question considered here of how income is evaluated and counted and how that compares with Medicaid standards and methodology.³¹ Benefit design studies that examine separate SCHIP programs confirm that these 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.³² Other recent CHIRI studies of separate SCHIP programs examine the characteristics of the children enrolled in the programs and key indicators of access to care, as well as disenrollment patterns and children's reasons for leaving the programs.³³ Together, these studies found a prevalence of children with special health care needs ranging from 17 to 25 percent in Florida, Kansas, and New York. They concluded that this prevalence is comparable to or slightly higher than the estimate of 18 percent of the general child population who is at risk of a chronic condition or has a higher than average need for services, and somewhat lower than the prevalence of special needs in Medicaid, confirming the need to take a closer look at access to services and quality of services rendered to these children under programs such as SCHIP that typically limit or exclude the types of services they need to maintain their functioning or prevent further deterioration of their health status. These studies also found that prior to SCHIP these children were pervasively uninsured and lacked alternative sources of care, and once enrolled, experienced significant rates of disenrollment.³⁴ Finally, they uncovered significant racial and ethnic disparities similar to those experienced by Medicaid children. Other state-based studies found that SCHIP improved access to care for these previously uninsured children, e.g., access to dental services.³⁵ None of these state-based studies, however, compared the experience of SCHIP children with Medicaid and/or privately-insured children.

D. Possible application of findings to actual MCH health care delivery situations

Which children would be most affected by this move away from Medicaid rules and toward insurance conventions? We believe that the implications would be greatest for two types of SCHIP-eligible children with special health care needs who would greatly benefit from improved access to MCH health care programs already in existence today.

The first group of children is made up of children with profound and potentially life threatening disabilities who need customized care of great intensity, such as ongoing therapies, private duty nursing, institutionalization, and hospice care. A considerable body of literature suggests that this group of children is exceedingly small. The second group of children is significantly larger and potentially harder to spot. These are children with physical, cognitive, and mental disabilities and delays that are perhaps not profound but that nonetheless are sufficient to cause limitations in daily activities and thwart normal growth and development. It is these children for whom Medicaid's preventive medical necessity standard may be the most important. The elimination of this standard, therefore, can be expected to have its most important impact on these children, leading to the potential for denial of treatment—or serious under-treatment.

The question is who will pay for this cluster of services for children with special health needs if Medicaid and SCHIP do not. In some states, the Title V Maternal and Child Health Services Block Grant Program may be a logical source of funding for children with extremely serious physical disabilities and conditions. But most Title V programs do not fund services for children with mental and developmental disabilities

and delays. For these services one would have to look to special education programs, state block grants for mental illness and mental retardation, and other grant-style programs. In either case, the coordination between SCHIP and these other sources of care, both at the program design and program implementation stages, becomes of the utmost importance in ensuring that these children gain access to the services they need.

E. Policy implications

The departures from Medicaid described in this study have important implications for pediatric health care, particularly for children with special health care needs.

On the one hand, the flexibility in program design under SCHIP allows states to extend coverage to higher family income levels and thus a higher number of uninsured children than they would have otherwise, had they not been able to exercise more control over the specific terms for providing that coverage. At the same time, the ability to use more limited benefit packages and higher cost-sharing, mandatory managed care enrollment for all children, and, when financially necessary, coverage waiting lists permits to exercise greater restraint over expenditures under the program.

On the other hand, this discretion has important implications for certain groups of children, i.e., those who find themselves on waiting lists for any coverage, as well as children with special health care needs whose health conditions place them beyond the limits of the coverage they receive. It is this second group in which we were interested in this study because of concerns that shortfalls in coverage for care could lead to insufficient access to medically necessary treatment and management services. This concern with the impact of more limited SCHIP products on children with special health care needs has taken on additional importance because of evidence of movement in the underlying Medicaid program toward more limited benefits and higher cost-sharing through legislative reform or the use of §1115 demonstration authority. It is important to know whether supplemental services or insurance would be necessary for certain children were coverage to be curtailed and, if so, for which children coverage and treatment supplements would be most significant.

F. Suggestions for further research

Several areas for further research derive directly from the findings of the various components of this study.

The findings from the in-depth descriptive study of the right to coverage under separate SCHIP programs suggest that a key area for further study is how a state's decisions regarding entitlement or restricted rights to coverage affect the overall administration of separate SCHIP programs. For example, the decision to mandate coverage, even only up to authorized limits, might lead states to offer fewer benefits, impose higher cost-sharing, or pay providers at a lower rate as techniques for controlling outlays. The absence of a legal entitlement or a restricted right to coverage might also affect the existence of waiting lists for coverage. The absence of a legal entitlement or

restricted right to coverage might affect participation in the program among providers concerned with the cessation or deferral of benefits for eligible children. Finally, the true effects of state decisions regarding the entitlement status of their programs may be visible only when economic conditions cause states to halt or slow spending that they otherwise would make in a full or limited entitlement situation. Thus, fully understanding the effects of state entitlement decisionmaking requires further research and monitoring over time.

Similarly, the findings from the series of comparative studies of eligibility criteria, benefit coverage, and managed care design features, coverage decisionmaking study and implementation case studies, showing that insurance design matters in terms of access to health care for children with special health care needs and that insurance products that are limited in their coverage of treatment and management of chronic conditions and illnesses affect the extent to which children with serious health problems use care, suggest that further research is needed to evaluate data on access and utilization of health services by children with special health care needs in the context of the detailed and extensive insurance design data developed for this study. An analysis of actual use of services, comparing SCHIP-covered children with special health care needs and similarly situated children enrolled in Medicaid would examine how these children fare on the ground. This research could test for health care differences that can be linked to the nature, quality and structure of children's insurance coverage, and determine whether key indicators of access differ significantly depending on type of coverage (i.e., Medicaid vs. separate SCHIP programs).

VI. List of Products

Peer-reviewed Articles

Rosenbaum, S., Smith, B., Sonosky, C., Repasch, L., and Markus, A. (2001) Devolution of Authority and Public Health Insurance Design: National SCHIP Study Reveals an Impact on Low-Income Children. 1 *Houston Journal of Health Law & Policy* 5: 33-61.

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