

# Children With Special Health Care Needs Enrolled in the State Children's Health Insurance Program (SCHIP): Patient Characteristics and Health Care Needs

Peter G. Szilagyi, MD, MPH\*; Elizabeth Shenkman, PhD‡; Cindy Brach, MPP§; Barbara J. LaClair, MHA||; Nancy Swigonski, MD¶; Andrew Dick, PhD\*; Laura P. Shone, MS\*; Virginia A. Schaffer, MA‡; Jana F. Col, MS‡; George Eckert, MAS¶; Jonathan D. Klein, MD, MPH\*; and Eugene M. Lewit, PhD#

**ABSTRACT.** *Background.* Children with special health care needs (CSHCN) often require more extensive services than children without special needs. The State Children's Health Insurance Program (SCHIP) in many states typically provides less extensive benefits and services than do state Medicaid programs. To design SCHIP to address the needs of CSHCN adequately, it is important to measure the degree to which children who enroll in SCHIP have special health care needs and to assess their health status and unmet health care needs. Little is known about the characteristics or preenrollment experience of CSHCN who enroll in SCHIP.

*Objectives.* To use data from the Child Health Insurance Research Initiative to measure the prevalence of CSHCN in SCHIP in 4 states, describe their demographic and health care features at enrollment, and compare their sociodemographic characteristics, health status, prior health care experiences, and unmet needs versus children without special health care needs.

*Methods.* Children (0–18 years old) newly enrolled in SCHIP in 4 states were eligible for the study: New York, Florida (adolescents only), Kansas, and Indiana (CSHCN only). Telephone interviews were conducted shortly after enrollment and identified CSHCN by using the Child and Adolescent Health Measurement Initiative CSHCN screener. A common set of core questions assessed demographic characteristics, health status, special health care need status, insurance experience, access, use, quality of health care, and unmet needs during the year before enrollment. Bivariate and multivariate analyses were used to compare characteristics of CSHCN with characteristics of children without special needs.

*Results.* Interviews were completed for parents of 5296 children enrolled in SCHIP in the 4 states. By using the Child and Adolescent Health Measurement Initiative CSHCN screener, the prevalence of CSHCN among

SCHIP enrollees was 17% (New York), 18% (Florida), and 25% (Kansas), higher than the prevalence of CSHCN reported in the general population in those states. More than half of CSHCN reported the use of a chronic medication. Demographic characteristics of CSHCN were similar to those of children without special needs, although CSHCN were more likely to reside in single-parent households. Although CSHCN had poorer health status than children without special needs, many CSHCN were reported to be in good health, suggesting a wide spectrum of severity of illnesses within the CSHCN group. Although CSHCN were more likely than children without special needs to have been insured before SCHIP, a large proportion of CSHCN were nevertheless uninsured for at least 12 months before SCHIP (New York, 56%; Florida, 68%; Kansas, 24%; Indiana, 25%). Although most SCHIP enrollees had a usual source of care (USC) before SCHIP and there was some variation across states, between 4% and 13% of CSHCN lacked a USC on enrollment, and 23% to 38% of CSHCN changed their USC after enrollment in SCHIP. The majority of all SCHIP enrollees (including CSHCN) had used some health care during the year before SCHIP including preventive, acute, or specialty care. A high proportion of all SCHIP enrollees, including >30% to 40% of CSHCN, were reported to have unmet health care needs at enrollment in SCHIP. A variety of unmet needs were reported by CSHCN including specialty care, mental health care, dental care, and prescription medications. Nevertheless, the vast majority of CSHCN as well as children without special needs rated the quality of their medical care before SCHIP highly on several specific quality measures. Findings from multivariate analyses were similar to bivariate results with CSHCN in several states having higher use of care and more unmet health care needs before enrollment.

*Conclusions.* SCHIP is enrolling many CSHCN, with the prevalence of these children occurring at least as high as the prevalence of CSHCN in the general population. CSHCN enrolled in SCHIP represent a heterogeneous population with a wide range of health status and health care needs. Although most CSHCN were already connected to the health care system with a USC and prior health care visits, many had unmet health care needs before enrolling in SCHIP.

*Implications for Monitoring and Improving SCHIP for CSHCN Enrollees.* 1) SCHIP benefit packages need to adequately cover services required by CSHCN such as prescription medications and specialty, mental health, developmental, and home services; 2) because utilization of care will be high among this large group of children, alternative methods of financing and managing care should be considered such as risk adjustment and special

From the \*Departments of Pediatrics and Community and Preventive Medicine, University of Rochester School of Medicine and Dentistry, Rochester, New York; †Institute for Child Health Policy, University of Florida, Gainesville, Florida; ‡Center for Delivery, Organization, and Markets, Agency for Healthcare Research and Quality, Rockville, Maryland; §Kansas Health Institute, Topeka, Kansas; ¶Departments of Pediatrics and Medicine, Indiana University School of Medicine, Indianapolis, Indiana; and #The David and Lucile Packard Foundation, Los Altos, California.

Received for publication Jun 25, 2003; accepted Aug 4, 2003.

Reprint requests to AHRQ Publications Clearinghouse, P.O. Box 8547, Silver Spring, MD 20907-8547. E-mail: ahrqpubs@ahrq.gov

This article represents the views of the authors and not necessarily those of the funding agencies.

This study was approved by the human investigations boards of each institution.

PEDIATRICS (ISSN 0031 4005). Copyright © 2003 by the American Academy of Pediatrics.

programs that involve case management and care coordination; 3) coordination of care across programs (such as between SCHIP and the state Title V Maternal and Child Health Services program, a component of which serves CSHCN) and ensuring adequate access to primary care and specialty providers might improve access to services for CSHCN; and 4) it is critical to monitor the quality of care for CSHCN enrolled in SCHIP, because these children are among the most vulnerable children covered by public health insurance programs and many of them are enrolling in SCHIP. *Pediatrics* 2003;112:e508–e520. URL: <http://www.pediatrics.org/cgi/content/full/112/6/e508>; *children with special health care needs (CSHCN); State Children's Health Insurance Program (SCHIP)*

---

ABBREVIATIONS. SCHIP, State Children's Health Insurance Program; CSHCN, children with special health care needs; FPL, federal poverty level; CMS, Children's Medical Services; USC, usual source of care; ED, emergency department.

---

The State Children's Health Insurance Program (SCHIP) was enacted by Congress to provide health insurance coverage to children in low-income families who are not eligible for Medicaid or covered by private health insurance. SCHIP legislation allows states to provide this coverage either by expanding Medicaid, developing free-standing separate insurance programs that are more like employer-sponsored private insurance, or a combination. Although Medicaid programs provide a rich set of services for children with special health care needs (CSHCN), free-standing SCHIP programs typically provide less extensive benefits. To design SCHIP to address the needs of CSHCN adequately, it is necessary to measure the degree to which children who enroll in SCHIP have special health care needs and to assess their health status and unmet health care needs at enrollment. As yet, little is known about the characteristics or preenrollment experience of CSHCN who enroll in SCHIP.<sup>1,2</sup>

There is no absolute consensus about how to define CSHCN.<sup>3</sup> In the past, CSHCN were defined by using categorical approaches such as the presence of specific diagnoses such as cancer or eligibility for specific programs such as the state Title V Maternal and Child Health Services program. Recently, a group of child health experts sponsored by the federal Maternal and Child Health Bureau identified CSHCN as "those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."<sup>3</sup> This broader definition is noncategorical and includes children with chronic physical, mental, developmental, and behavioral needs.

Some instruments have been developed that identify CSHCN by using a noncategorical approach.<sup>4–9</sup> Two analyses that applied this noncategorical definition of CSHCN to the 1994 National Health Interview Survey estimated a national prevalence of CSHCN in the general population to be between 14.8%<sup>10</sup> and 18.2%.<sup>11</sup> A major new national survey, the National Survey of Children with Special Health

Care Needs,<sup>12,13</sup> soon will provide data on ~750 CSHCN per state. However, the number of CSHCN within SCHIP may be too low per state to assess how well SCHIP is meeting the health care needs of enrollees. Furthermore, national surveys tend not to distinguish SCHIP from other health insurance programs. Thus, state-based evaluations are needed.

Although noncategorical approaches for identifying CSHCN have been proposed as Health Plan Employer Data and Information Set measurements,<sup>14,15</sup> they are not used widely by SCHIP or Medicaid managed care plans. State SCHIP strategies tend to follow the definitions of their state Medicaid programs,<sup>16,17</sup> using available administrative data<sup>18</sup> to identify children by the presence of specific diagnoses, a high level of services or costs, or enrollment in a special program such as the Title V Maternal and Child Health Services program.<sup>19</sup> Because of the lack of uniformity in definition and the inability to even identify the CSHCN population within SCHIP, little is known about CSHCN enrolled in SCHIP.

Regardless of which criteria for CSHCN identification are used, many studies have noted that CSHCN have poorer health status, higher health care needs, higher use of outpatient and inpatient services, more frequent use of specialty services and ancillary services, and higher health care costs than the general population of children.<sup>20–30</sup>

This study is part of the Child Health Insurance Research Initiative, funded by the Agency for Health Care Research and Quality, The David and Lucile Foundation, and the Health Resources and Services Administration. Study objectives are to 1) determine the prevalence of CSHCN among enrollees in SCHIP in several state programs, 2) describe sociodemographic and health characteristics of CSHCN, and 3) compare CSHCN versus children without special needs with respect to demographic characteristics, health status, prior insurance, prior health care experience, and prior unmet health care needs. We hypothesized that 1) SCHIP would enroll fewer CSHCN than their prevalence in the general population, because many might have been enrolled in other programs, 2) CSHCN who do enroll in SCHIP would already be higher users of health care than other children because of their chronic conditions, but 3) CSHCN would enter SCHIP with many unmet needs.

## METHODS

The study methods are summarized in Table 1, with states listed according to the size of the SCHIP program in each state.

### Setting

SCHIP in 4 states (New York,<sup>31</sup> Florida,<sup>32</sup> Kansas, and Indiana) were evaluated. The bulk of SCHIP enrollees in New York and Florida and all enrollees in Kansas are enrolled in free-standing separate SCHIP programs, whereas Indiana has more children enrolled in the Medicaid-expansion portion of its SCHIP program. The New York and Florida programs are large and mature, because both had prototype insurance programs before SCHIP.<sup>33,34</sup> The Kansas and Indiana programs are newer, having begun in 1998 and 1999, respectively.<sup>35</sup> Together, these 4 states had 1.2 million SCHIP enrollees in 2001, which comprised 26% of the nation's SCHIP enrollment.<sup>36</sup>

With the exception of Florida, most CSHCN were enrolled into

**TABLE 1.** Study Sample and Methods by State

	New York	Florida	Kansas	Indiana
Program name	Child Health Plus	Healthy Kids	HealthWave	Hoosier Healthwise
Program structure*	Combination†	Combination‡	Separate SCHIP	Combination§
Year implemented	1991	1992	1999	1999
Ever enrolled during 2001¶	872 949	298 705	34 241	56 986
Sampling frame	Enrolled in SCHIP between 11/1/00 and 3/31/01; no SCHIP enrollment in prior 24 months	Enrolled in SCHIP for <3 months with new enrollment occurring between 7/1/00 and 12/31/00	Enrolled in SCHIP between 9/1/00 and 12/31/00; no SCHIP enrollment in prior 6 months	CSHCN enrolled in SCHIP between 8/1/00 and 2/1/01; no SCHIP enrollment in prior 3 months
Sampling method	Random; one unique child per family	Random; one unique child per family	Random; one unique child per family	Convenience**; one unique child per family
Stratification	Age; race/ethnicity; geographic region	None	Age; urbanicity	None
Results weighted	Yes	Yes	Yes	No
Analytic software used	STATA, Version 7.0	SUDAAN, Version 8.0.1	SUDAAN, Version 8.0.1	SAS, Version 8.0.2
Age range (years)	0–17.9	11.5–17.9	0–17.9	0–17.9
Surveys completed between:	3/15/01 and 9/18/01††	1/8/01 and 8/1/01	10/9/00 and 4/29/01	9/12/00 and 4/15/01
No. of cases	2,620	1,824	776	76

This table reflects program characteristics in 2001. Characteristics may have changed since then.

\* With the exception of Indiana, where the Medicaid expansion portion of SCHIP represents a significant proportion of SCHIP enrollees, the data in this article include only new enrollees of separate, free-standing SCHIP programs (ie, Medicaid expansion SCHIP enrollees were not included).

† New York's Medicaid expansion covered children 15–18 years to 100% federal poverty level (FPL) who were not otherwise eligible for Medicaid.

‡ Florida's Medicaid expansion covered children <1 and 17–18 years to 100% of FPL who were not otherwise eligible for Medicaid.

§ Indiana's Medicaid expansion covered all children up to 150% of FPL who were not otherwise eligible for Medicaid.

|| Florida and New York had state-specific SCHIP precursor programs that became their respective SCHIP programs after the passage of Title XXI.

¶ Entries on this row represent the total number of enrollments during federal fiscal year 2001.

\*\* All families enrolling in Indiana SCHIP were provided a 1-page letter inviting participation in the study; those who gave permission for the study were contacted by the Indiana study team. Although <2% of the forms received by the study team indicated refusal to participate, on some busy days in certain locations the permission forms were not distributed; thus the sample is technically a convenience sample.

†† Less than 20 interviews were completed after 9/11/01; all others were completed prior to that date.

SCHIP in the same manner as other children. Florida has a carve-out program for CSHCN eligible for Medicaid or SCHIP called Children's Medical Services (CMS), which is part of Florida's state Title V Maternal and Child Health Services program. Florida children are identified through the SCHIP enrollment process as potential eligible CMS enrollees by using 3 screening questions modified from the CSHCN screener. More severely disabled CSHCN are referred from SCHIP to CMS.<sup>37</sup> In all states, children with disabling special needs may be eligible for special programs such as the Supplemental Security Income program, Medicaid "medically needy programs," Katie Beckett Waivers, and Title V Maternal and Child Health Services programs,<sup>2</sup> which may provide additional services or opportunity for enrollment in Medicaid.

### Study Design

Comprehensive telephone interviews were performed 2 to 7 months after enrollment in SCHIP. The interviews addressed demographic and health care information during the year before enrollment in SCHIP. A core set of questions was developed across the 4 states to obtain similar information. The presence of special needs was assessed by using the CSHCN screener (see Table 2, described more completely below), a widely used 5-question screener identical to the one used in the National Survey of Children with Special Health Care Needs<sup>8,9,12,13</sup> and one that is in the CSHCN module recently approved by the National Committee on Quality Assurance for optional use by Health Plan Employer Data and Information Set performance-measure assessments.<sup>14,15</sup>

### Study Participants

Participants included all children with completed parent interviews after first-time enrollment in SCHIP (ie, never before en-

rolled in the state's SCHIP or pre-SCHIP insurance initiative). In New York, the study design<sup>31</sup> involved a stratified sample of children based on geography, race, and ethnicity with results weighted to reflect the state's newly enrolled SCHIP population. The Florida study<sup>32</sup> focused on adolescents 11.5 to 18 years old who were not enrolled in CMS; in the other states, children 0 to 18 years old were sampled. The Kansas sample<sup>38</sup> of children newly enrolled in SCHIP was stratified by age and urbanicity with results weighted to reflect the population of new SCHIP enrollees. In Indiana,<sup>39</sup> a convenience sample of children was screened at new enrollment into SCHIP (during some extremely busy enrollment days, screening was not done because of resource limitations), and children who screened positive on the CSHCN screener were included.

### Telephone Interviews

Study teams obtained the list of SCHIP enrollees from their states, and telephone calls were made at varying times of the day and week. Altogether, 5296 parent interviews were completed: 2620 in New York, 1824 in Florida, 776 in Kansas, and 76 in Indiana.

### Socioeconomic, Demographic, and Health Status Measures (Table 3)

These measures included the child's age group, gender, race and ethnicity, urbanicity, income, family structure, respondent education and employment, and 3 commonly used health status questions.

### CSHCN Measures

CSHCN were identified by a positive response on the CSHCN screener (see Table 2). The scoring algorithm<sup>40</sup> recommended by the

**TABLE 2.** CSHCN as Identified by the CSHCN Screener

Overall-CSHCN Screener*	% of Children Identified as CSHCN (SEs)					
	New York		Florida		Kansas	
	16.5% (n = 435)		18.2% (n = 331)		25.3% (n = 196)	
Each Item-CSHCN Screener*	%	% Yes to This Alone	%	% Yes to This Alone	%	% Yes to This Alone
1) Does your child need or use more medical care, mental health, or educational services than is usual for most children of the same age?	6.7 (1.4)	0.79 (0.21)	7.1 (0.60)	0.55 (0.17)	12.9 (1.4)	1.5 (0.5)
2) Does your child currently need or use medicine prescribed by a doctor, other than vitamins?	10.8 (1.7)	6.4 (1.4)	11.4 (0.75)	5.3 (0.52)	17.3 (1.6)	6.6 (1.0)
3) Is your child limited or prevented in any way in his or her ability to do the things most children of the same age can do?	3.4 (0.99)	0.53 (0.20)	5.1 (0.52)	1.1 (0.24)	7.8 (1.1)	0.6 (0.3)
4) Does your child need or get special therapy such as physical, occupational, or speech therapy?	1.9 (0.41)	0.57 (0.20)	1.4 (0.28)	0.22 (0.11)	5.3 (0.34)	0.8 (0.4)
5) Does your child have any kind of emotional, developmental, or behavioral problem for which he or she needs treatment or counseling?	4.2 (1.0)	0.95 (0.29)	7.5 (0.62)	2.4 (0.36)	8.3 (1.1)	0.9 (0.4)
7 Possible combinations of special needs†						
1) Dependency only	6.4 (1.4)	—	4.3 (0.47)	—	6.6 (1.0)	—
2) Functional limits only	0.53 (0.20)	—	5.3 (0.52)	—	0.6 (0.3)	—
3) Service use only	4.6 (1.1)	—	1.1 (0.24)	—	5.2 (0.9)	—
4) Dependency + service use	2.1 (0.58)	—	3.4 (0.42)	—	5.7 (1.0)	—
5) Dependency + functional limits	0.61 (0.21)	—	0.50 (0.17)	—	1.1 (0.5)	—
6) Service use + functional limits	0.58 (0.16)	—	1.2 (0.26)	—	2.2 (0.6)	—
7) Dependency + functional limits + service use	1.7 (0.94)	—	2.3 (0.35)	—	3.9 (0.8)	—

In Indiana, screening was conducted by state enrollment staff, and data are not available about prevalence of CSHCN. SE indicates standard error of the mean.

\* A positive response on each question is indicated only if parts “a” (“Is this because of any medical, behavioral, or other health condition?”) and “b” (“Is this a condition that has lasted or is expected to last 12 months or longer?”) are both affirmed.

† Three “definitional domains” exist: 1) dependency on prescription medications, 2) functional limitations, and 3) service use above normal.

Child and Adolescent Health Measurement Initiative and the Foundation for Accountability was followed to identify a CSHCN (yes/no) if the parent responded affirmatively to at least 1 of the 5 questions and follow-up subquestions designed to determine if the child had a physical or mental health condition that had lasted or was expected to last for at least 12 months. The scoring algorithm also identified the different domains of CSHCN (see Table 2).<sup>40</sup>

**Access, Utilization, and Quality**

The major comparison involved CSHCN versus the remainder of SCHIP enrollees (before enrollment in SCHIP) within each state for 1) prior insurance variables (the number of uninsured months during the year before SCHIP, the type of most recent insurance, and reasons for loss of prior insurance); 2) presence of a usual source of care (USC) before enrollment in SCHIP, type of source, reasons for lack of a source of care, and change in the USC after enrollment; 3) use of health care before SCHIP (any use and number of visits); 4) unmet needs before enrollment; and 5) quality of care (continuity, specific quality markers regarding provider’s care, and satisfaction with care).

**Analyses**

Descriptive statistics ( $\chi^2$  analyses or *t* tests) were used to tabulate proportions of SCHIP enrollees who were CSHCN and to compare characteristics of CSHCN versus children without special needs.

We used multivariate methods to generate “adjusted” rates for 5 key measures of health care access: 1) having a USC; 2) use of the emergency department (ED); 3) use of preventive care; 4) unmet needs; and 5) prior insurance. All sociodemographic measures from Table 3 were included in the multivariate analyses for the first 3 models; prior insurance was omitted as an independent variable in the fourth model because it was the dependent mea-

sure. For the first 4 dichotomous dependent variables, we estimated multivariate logistic regressions to examine the independent association with CSHCN, controlling for other sociodemographic characteristics. For prior health insurance, which has 3 levels (none, Medicaid, and private/other), we estimated a multivariate multinomial logistic regression model.

Adjusted estimates were calculated for the CSHCN group and for other children by predicting the outcomes for all children in the sample after setting the special needs variables to CSHCN first and then to “other children.” The differences in the adjusted estimates between CSHCN and other children reflect outcomes that may be attributed to CSHCN. For ease of interpretation, all multivariate models were run with no interaction terms; otherwise, models across states would have had varying components and been difficult to compare. All analyses were weighted to be representative of the SCHIP populations by state using STATA 7.0, SUDAAN 8.0.1, or SAS 8.0.1 to adjust for the complex survey designs in each state.

**RESULTS**

**Prevalence of CSHCN Among SCHIP Enrollees (Table 2)**

The prevalence of CSHCN among SCHIP enrollees was 17% in New York, 18% in Florida, and 25% in Kansas. Table 2 also shows the percentage of all SCHIP enrollees who screened positive on each of the 5 CSHCN screener questions and the percentage that screened positive only for one particular question. Chronic medication use was most common, cited by 10.8% (New York) to 17.3% (Kansas) of all SCHIP enrollees; 5.3% (Florida) to 6.6% (Kansas)

**TABLE 3.** Demographic Characteristics of CSHCN Versus All Other Children at SCHIP Enrollment

	New York		Florida		Kansas		Indiana
	CSHCN	Other	CSHCN	Other	CSHCN	Other	CSHCN
Child age group†							
0–2 years	13.0%	21.3%*		NA	4.5%	18.0%***	7.9%
3–5 years	11.5%	19.1%*		NA	16.2%	15.6%	10.5%
6–11 years	45.2%	31.6%		NA	44.7%	37.9%	47.4%
12–18 years	30.3%	28.1%	100.0%	100.0%	34.6%	28.6%	34.2%
Gender:							
Male	44.1%	49.6%	55.8%	49.0%*	60.8%	49.2%*	65.8%
Race and ethnicity							
White (non-Hispanic)	29.4%	23.7%	62.8%	54.1%	71.8%	63.5%	77.6%
Black (non-Hispanic)	29.6%	30.8%	13.5%	16.3%	8.5%	12.6%	10.5%
Hispanic	41.0%	45.5%	22.2%	26.6%	10.0%	16.7%*	6.6%
Other		NA	1.5%	3.1%	9.7%	7.2%	5.3%
Single-parent household	60.1%	49.1%	48.6%	41.5%*	50.5%	42.6%	47.3%
Household size:							
Mean	4.1	4.3	3.8	3.9	3.8	4.0	NA
Standard error	0.16	0.08	0.08	0.03	0.2	0.1	NA
Family income							NA
≤150% FPL	76.3%	79.3%	63.0%	65.4%	72.7%	66.0%	
>150% FPL	23.7%	20.7%	37.0%	34.6%	27.3%	34.0%	
Residence							
Metropolitan	91.8%	92.9%	92.6%	91.8%	42.7%	43.7%	61.8%
Large town	2.3%	2.4%	5.9%	7.1%	35.9%	28.7%	22.4%
Small town/rural	5.9%	4.7%	1.5%	1.2%	21.4%	27.5%	15.8%
Highest grade completed‡							
<High school	28.0%	27.3%	14.6%	14.7%	3.6%	7.1%	11.8%
High school grad or GED	30.9%	39.0%	34.8%	38.7%	59.2%	57.3%	39.5%
Technical/vocational	0.5%	0.6%	5.2%	4.0%	NA	NA	NA
Some college	28.0%	21.0%	24.1%	22.8%	25.3%	20.9%	35.5%
College graduate and higher	12.7%	12.1%	21.3%	19.8%	11.8%	14.7%	13.2%
Employment status§							
Working full-time 35+ hours	31.5%	42.8%	50.9%	53.1%	51.3%	43.4%	27.6%
Working part-time <35 hours	25.7%	20.9%	13.2%	12.1%	14.1%	16.2%	19.7%
Staying at home	32.6%	29.3%	23.0%	25.1%	NA	NA	27.6%
Going to school	0.6%	4.5%***	1.6%	1.8%	NA	NA	3.9%
Other	9.6%	2.6%***	11.3%	7.9%*	6.6%	31.7%	21.2%
Not working	25.6%	18.3%	25.6%	18.3%	28.0%	31.7%	NA
Second parent working	26.0%	33.0%	32.3%	41.9	38.1%	47.8%	NA
Child's health status							
Excellent or very good	33.0%	46.9%*	54.1%	77.2%***	41.5%	82.8%***	42.1%
Good	49.1%	43.4%	31.8%	18.9%***	39.2%	13.1%***	36.8%
Fair	17.2%	9.3%	11.9%	3.5%***	15.3%	3.9%***	15.8%
Poor	0.7%	0.4%	2.1%	0.27%***	4.0%	0.23%*	5.3%
Worry about child's health							
None	26.9%	38.9%	35.5%	68.8%***		NA	31.5%
Little	29.2%	24.7%	24.2%	18.3%*			26.0%
Some	19.4%	12.9%	15.6%	6.9%***			12.3%
Quite a bit	11.4%	12.3%	12.8%	3.4%***			9.6%
A lot	19.8%	20.3%	11.9%	2.6%***			20.6%
Child less healthy than others	21.9%	8.0%**	19.8%	8.4%		NA	42.5%

NA indicates not applicable.

Significance testing is for CSHCN vs. others within the same state (\*  $P \leq .05$ ; \*\*  $P \leq .01$ ; \*\*\*  $P \leq .001$ ).

† Florida sampled adolescents only; the Kansas adolescent age range included 12–17 years.

‡ Maximum education (respondent or parent/head of household)

§ Maximum employment in household (respondent or parent/head of household)

screened positive based only on that single question. The next most common CSHCN screener question that identified CSHCN involved needing or using more care than usual, followed by having an emotional, developmental, or behavioral problem that needs treatment.

The largest proportion of children screened on one dimension of special need alone (dependency on prescription medications, functional limitation, or service use above normal). However, 1.7% (New York) to 3.9% (Kansas) of children had all 3 dimensions of need.

### Demographic and Health Characteristics of CSHCN Versus Other SCHIP Enrollees (Table 3)

Although CSHCN tended to be older and more likely to reside in a single-parent household, large demographic differences between CSHCN and other children were not noted. The majority of children, including those identified as CSHCN, were described by parents as having excellent, very good, or good health. However, there was a clear trend toward CSHCN having poorer health status than other children. A high proportion of parents reported wor-

rying about their child's health, and in Florida the level of worry was higher for CSHCN.

Table 4 summarizes the prior health insurance experience of CSHCN versus other children. Four major findings are noted. First, there was a trend toward CSHCN being more likely than children without special needs to have been insured before SCHIP. Second, in most states there seem to be 2 predominant patterns of prior insurance: children covered for the entire 12 months (ie, enrolled immediately in SCHIP after their previous coverage ended) or children uninsured for the entire year before SCHIP. Florida differed in this regard in that fewer children were covered for the entire 12 months and more had private insurance before enrolling in SCHIP. Third, although there were variations by state, a substantial proportion of children had Medicaid as their most recent prior insurance. Fourth, the major reasons for loss of prior insurance involved a parent's employment change, the high costs of the prior insurance, the perception that there would be better benefits from SCHIP compared with their prior insurance, or a life change (particularly loss of Medicaid because of rising income).

The vast majority of all SCHIP enrollees (79% to >90%) had a USC during the year before SCHIP (Table 5). Although there appeared to be trends toward CSHCN being more likely to have a USC before enrolling, these differences generally did not reach statistical significance. In the 2 largest states (New York and Florida), ~10% of CSHCN had no USC before SCHIP. The most common type of prior

USC for all SCHIP enrollees was a doctor's office outside of the hospital, followed by community health centers and hospital clinics. The type of USC differed across states, with Florida SCHIP enrollees being less likely than enrollees from other states to have received care from hospital-based clinics previously. A common reason for not having a USC was lack of health insurance. The reasons varied widely across states. In general, CSHCN were less likely than children without special needs to cite never being sick as a reason for not having a USC.

Approximately one third of children in each state changed their USC after enrolling in SCHIP. The Kansas survey asked about the reasons for changing USC, and they were: previous place did not accept SCHIP (CSHCN, 41%; other, 45%); parent wanted a different place (CSHCN, 39%; other, 34%); or family moved (CSHCN, 34%; other, 25%).

Many children, both with and without special needs, used health services during the year before SCHIP (Table 6). This includes a high proportion using the ED, >65% having a preventive visit, and a substantial proportion having an acute visit. Although there was some variability across states in the use of health care and not all visit types were assessed by all states, CSHCN were more likely than children without special needs to use the ED, mental health care, specialty care, and acute care.

Although the questions on unmet health care needs (Table 7) varied somewhat across the states, they were identical within each state for all interviewed children, making it feasible to compare

TABLE 4. Prior Insurance Experience of CSHCN Versus All Other Children

	New York		Florida		Kansas		Indiana
	CSHCN	Other	CSHCN	Other	CSHCN	Other	CSHCN
No. of months insured during							
Year before SCHIP							
All 12 months	31.9%	21.9%	6.5%	4.3%	47.3%	43.1%	56.9%
9-11 months	4.1%	4.4%	9.9%	6.9%	9.4%	6.1%	4.2%
6-8 months	2.7%	5.4%*	9.0%	8.9%	13.3%	8.1%	9.7%
3-5 months	3.1%	3.2%	4.3%	4.4%	3.9%	5.6%	2.8%
1-2 months	0.8%	1.9%*	1.9%	1.7%	2.6%	3.1%	1.4%
None (uninsured all year)	56.4%	62.9%	68.3%	73.7%*	23.6%	34.1%*	25.0%
Type of last insurance†							
Private employer-sponsored	37.4%	49.6%	56.0%	60.3%	17.8%	20.5%	53.8%
Private other	4.8%	1.4%*	6.0%	11.3%	0.0%	0.9%*	3.1%
Medicaid	38.7%	43.5%	27.0%	20.9%	61.1%	52.9%	38.5%
Other	26.3%	9.5%*	11.0%	7.5%	21.1%	23.9%	4.6%
Reason for loss of prior insurance††							
Life change							
Separation, divorce, death	7.1%	4.7%	7.5%	7.3%	9.6%	5.6%	8.3%
Aged out of Medicaid,	1.8%	2.8%	1.7%	1.6%	NA		8.3%
Lost Medicaid (income)	30.4%	19.1%	5.0%	4.7%	10.4%	8.2%	8.3%
Employment change							
Lost or changed job	25.0%	24.8%	47.9%	44.0%	31.0%	30.1%	41.7%
Employer stopped coverage	4.6%	10.5%	11.3%	7.8%	3.0%	2.2%	NA
Costs or benefits							
High cost of prior insurance	15.2%	22.6%	18.3%	26.9%**	19.9%	29.0%	62.5%
SCHIP cost less	19.7%	24.2%	3.3%	4.0%	NA		45.5%
SCHIP has better benefits	32.6%	28.1%	0.42%	1.5%	NA		47.8%
Other	23.8%	33.9%	4.6%	2.4%	27.0%	26.8%	NA

NA indicates not applicable. Florida sampled adolescents only; the Kansas adolescent age range included 12-17.9 years.

Significance testing is for CSHCN versus others within the same state (\* $P \leq .05$ ; \*\* $P \leq .01$ ).

† For the subset of children who had any prior insurance before SCHIP.

†† More than one reason was accepted in New York, Kansas, and Indiana.

**TABLE 5.** USC of CSHCN Versus All Other Children

	New York		Florida		Kansas		Indiana
	CSHCN	Other	CSHCN	Other	CSHCN	Other	CSHCN
Had USC before SCHIP	90.5%	85.6%	87.2%	79.4%***	92.8%	89.5%	95.9%
Type of USC place							
Hospital ED	1.7%	5.5%	4.0%	3.8%	0.4%	0.4%	0.0%
Clinic or office in a hospital	25.2%	20.2%	4.0%	8.1%	14.5%	7.6%*	19.7%
Doctor's office outside hospital	48.1%	41.0%	63.2%	60.7%	67.9%	76.1%	63.4%
Health maintenance organization	1.9%	1.7%	5.4%	4.7%	2.8%	1.8%	5.6%
Neighborhood health center	6.5%	22.4%***	10.5%	10.1%	NA	NA	8.5%
Health department clinic	9.0%	4.6%	4.0%	4.8%	1.7%	4.4%	0.0%
Other	7.6%	4.6%	9.0%	7.5%	12.7%	9.6%	2.8%
Reason for no USC†							
Never sick	0.9%	21.1%***	40.5%	59.4%*	39.2%	57.9%	NA
Recently moved into area	33.5%	10.1%*	0	2.1%	44.7%	18.8%	
No insurance	21.5%	36.4%	16.7%	14.0%	67.9%	37.7%	
Cost	6.9%	3.3%	28.6%	19.8%	59.4%	48.8%	
Other	37.1%	26.6%	2.4%	2.1%	NA	NA	
Changed USC after enrolling in SCHIP‡	38.0%	42.0%	35.4%	31.0%	23.5%	30.9%	33.3%

NA indicates not applicable.

Significance testing is for CSHCN versus others within the same state (\*  $P \leq .05$ ; \*\*\*  $P \leq .001$ ).

† For children without a USC; more than one reason was accepted.

‡ For the subset of children who had any USC before SCHIP.

**TABLE 6.** Use of Health Care During Year Prior to SCHIP for CSHCN Versus All Other Children

Visits During Year Before SCHIP	New York		Florida		Kansas		Indiana
	CSHCN	Other	CSHCN	Other	CSHCN	Other	CSHCN
ED							
Any visit	30.3%	22.8%	37.0%	24.9%***	46.9%	30.3%***	38.2%
No. of visits	0.95	0.56*	0.70	0.43	1.2	0.47**	0.7
Total outpatient—any visit†	93.7%	85.2%**	88.7%	72.0%***	94.7%	93.6%	85.5
Mental Health							
Any visit	39.1%	17.2%***	NA	NA	25.3%	4.1%***	NA
No. of visits	0.59	0.25*	NA	NA	2.8	0.18***	NA
Specialty							
Any visit	34.6%	10.8%***	33.7%	13.4%***	NA	NA	50.0%
No. of visits	2.2	0.49	NA	NA	NA	NA	NA
Acute							
Any visit	30.6%	28.5%	48.8%	28.8%***	NA	NA	50.0%
No. of visits	1.6	0.97*	NA	NA	NA	NA	NA
Preventive							
Any visit	70.9%	73.9%	82.4%	65.3%***	68.3%	67.1%	69.7%
No. of visits	3.7	1.8	NA	NA	1.3	1.0	3.7
Dental							
Any visit	60.3%	45.3%*	NA	NA	63.8%	63.4%	73.7%
No. of visits	1.5	1.2	NA	NA	1.3	1.5	1.4

NA indicates not applicable.

Significance testing is for CSHCN versus others within the same state (\*  $P \leq .05$ ; \*\*  $P \leq .01$ ; \*\*\*  $P \leq .001$ ).

† Includes mental health, specialty, acute, or preventive visit.

CSHCN versus children without special needs within states. Three major findings are noted. First, a high proportion of all SCHIP enrollees (25% to nearly 50% depending on the state) had some kind of unmet health care need during the year before SCHIP. Second, there was a trend toward CSHCN having more unmet needs than other children in all 3 states that asked the question, and in Florida and Kansas these trends reached statistical significance for any need and several specific areas of need. Third, the major reasons for unmet health care needs were similar across states, with financial barriers being most prevalent but practice-level barriers (eg, couldn't get an appointment) and system-level barriers (eg, couldn't get a referral) also being important reasons. These reasons were similar for CSHCN versus children without special needs. Even among the Indiana

CSHCN, who had lower unmet needs for specific services than CSHCN in other states, the most prominent reasons for unmet needs before SCHIP were financial ones.

Table 8 displays results of several specific questions regarding quality of care given by children's providers before SCHIP. For all 4 questions, the quality of the provider's care was rated highly, with CSHCN having similar ratings as children without special needs. Approximately 25% of parents reported that providers only sometimes or never spent enough time with their child. Overall ratings of the provider were also high and similar for the 2 groups in each state.

Table 9 shows both unadjusted rates (from prior tables) and adjusted rates of key health measures using multivariate analyses as well as statistical sig-

**TABLE 7.** Unmet Health Care Needs of CSHCN Versus All Other Children

	New York		Florida		Kansas		Indiana
	CSHCN	Other	CSHCN	Other	CSHCN	Other	CSHCN
Any unmet health care need	43.6%	31.1%	61.9%	44.8%***	45.8%	28.1%***	NA
Specific unmet need							
Mental health	41.7%	25.4%	31.4%	22.2%	7.1%	0.73%**	NA
Specialty	43.1%	29.1%	NA	NA	NA	NA	11.6%
Acute care	15.8%	19.1%	NA	NA	16.1%	8.4%*	NA
Preventive care	15.6%	14.2%	7.7%	4.3%	NA	NA	NA
Dental care	28.6%	26.3%	31.9%	21.9%**	29.7%	29.6%	7.9%
Prescription medications	18.7%	16.4%	5.7%	12.0%	11.6%	4.6%*	1.5%
Vision care	16.3%	21.4%	NA	NA	NA	NA	NA
Reason for unmet need					NA		
Practice-level barrier							
Couldn't get appointment	25.9%	43.2%	13.5%	7.7%			15.8%
Couldn't reach by phone	16.6%	31.9%	NA	NA			2.6%
Not open when needed	21.9%	30.0%	6.3%	3.3%			9.2%
Transportation	30.0%	22.6%	9.9%	5.7%			2.6%
Financial barrier							
Too expensive	78.6%	69.3%	77.5%	72.0%			27.6%
Insurance didn't cover	82.6%	65.8%*	20.7%	8.1%			13.2%
System barrier							
Couldn't get referral	22.2%	29.2%	NA	NA			NA
Didn't know where to go	40.7%	34.4%	NA	NA			NA

The specific questions on unmet needs varied somewhat across states. In New York, a series of questions asked whether the child needed care, received care (yes/no), found it hard to get, delayed, or did not get care; in Florida, whether the child needed care, received care (yes/no), and reasons for not getting care; in Kansas, whether the child did not get or postponed getting care; and in Indiana, the items are in response to problems getting needed health care (yes/no). Relevant comparisons are between CSHCN and other children within each state. NA indicates not applicable.

Significance testing is for CSHCN versus others within the same state (\*  $P \leq .05$ ; \*\*  $P \leq .01$ ; \*\*\*  $P \leq .001$ ).

**TABLE 8.** Quality of Care of CSHCN versus All Other Children

	New York		Florida		Kansas		Indiana
	CSHCN	Other	CSHCN	Other	CSHCN	Other	CSHCN
My provider:							
Listens carefully to me							
Usually or always	77.9%	76.8%	82.2%	87.9%	85.9%	91.8%	95.8%
Sometimes or never	22.1%	23.2%	17.8%	12.1%	14.1%	8.2%	4.2%
Explains things in an understandable way							
Usually or always	88.8%	80.4%	85.9%	88.4%	91.5%	93.0%	94.4%
Sometimes or never	12.2%	19.6%	14.1%	11.6%	8.5%	7.0%	5.6%
Respects what I have to say							
Usually or always	92.8%	85.0%	82.9%	87.5%	92.4%	91.4%	94.4%
Sometimes or never	8.2%	15.0%	17.1%	12.5%	7.1%	8.6%	5.6%
Spends enough time with me							
Usually or always	74.5%	76.4%	74.1%	79.1%	NA		88.9%
Sometimes or never	26.5%	13.6%	25.9%	20.9%			11.1%
Mean rating of provider (1–10, 10 being highest)	8.6	8.5	8.7	8.7	8.3	8.6	8.7

These questions were adapted from the Consumer Assessment of Health Plan Survey. Each question had four responses (usually, always, sometimes, and never); results are collapsed for ease of presentation. NA indicates not applicable.

nificance for the main effects of CSHCN. Several findings are noted. First, the adjusted values all closely approximated the unadjusted values, which suggests that controlling for the sociodemographic characteristics did not alter the bivariate findings. Findings indicate that many children (22–75%) had no insurance, and 10% of children lacked a USC in the year before SCHIP. Despite having a high rate of preventive care visits (65–82%), many children had ED visits (23–50%) and unmet health care needs (27–62%) before SCHIP. Because sociodemographic characteristics of CSHCN and other children were similar (Table 3), this is not an unexpected finding. Second, CSHCN differed from other children from the same state on several measures. CSHCN from Florida

were more likely than other children to have had private insurance, and CSHCN from Kansas were less likely than other children to have had Medicaid before SCHIP. CSHCN in Florida were more likely to have had a USC than other children. In all 3 states, CSHCN were more likely to have used the ED, and in Florida they were also more likely to have used preventive care. In all 3 states, CSHCN seemed to have more unmet health care needs than other children from the same states (in New York, trends were noted).

## DISCUSSION

Contrary to our first hypothesis, the prevalence of CSHCN in SCHIP in the study states (17%, 18%, and

**TABLE 9.** Unadjusted and Adjusted Health Care Measures for CSHCN Versus Other Children

	New York		Florida		Kansas	
	CSHCN	Other	CSHCN	Other	CSHCN	Other
Prior insurance before SCHIP†						
Private/other						
Unadjusted	56.7%	62.8%	21.3%	20.7%	31.8%	31.0%
Adjusted	24.9%	21.6%	10.8%	7.1%*	33.3%	32.0%
Medicaid						
Unadjusted	16.1%	16.0%	9.7%	5.8%**	46.6%	36.1%*
Adjusted	18.5%	15.6%	18.8%	18.2%	44.6%	36.9%
None						
Unadjusted	56.7%	62.8%	69.0%	73.5%*	21.6%	32.9%*
Adjusted	56.6%	62.9%	70.4%	74.7%	22.0%	31.1%*
Had USC before SCHIP						
Unadjusted	90.5%	85.6%	87.2%	79.4%***	92.8%	89.5%
Adjusted	88.0%	85.4%	86.9%	78.7%**	92.0%	89.3%
Used care before SCHIP						
ED						
Unadjusted	30.3%	22.8%	37.0%	24.9%***	46.9%	30.3%***
Adjusted	32.9%	23.1%***	37.1%	25.5%***	50.0%	28.1%***
Preventive care						
Unadjusted	70.9%	73.9%	82.4%	65.3%***	68.3%	67.1%
Adjusted	71.9%	73.4%	82.3%	65.3%***	68.6%	67.2%
Any Unmet need before SCHIP						
Unadjusted	43.6%	31.1%	61.9%	44.8%***	45.8%	28.1%***
Adjusted	40.9%	31.6%	62.3%	45.5%***	46.4%	27.5%***

Adjusted results from multivariate testing are shown on the second row for each variable.

Multivariate models include variables from Table 3 (CSHCN status, age, race, gender, single household, household size, income, education, employment, and insurance type [for variables other than prior insurance]).

*P* values represent main effects of CSHCN (\* *P* ≤ .05; \*\* *P* ≤ .01; \*\*\* *P* ≤ .001).

† For clarity of analysis, the three prior insurance categories were private/other (private employer-sponsored health insurance + private other + other, from Table 4), Medicaid, and none. *P* values represent Medicaid versus none or private versus none.

25%) was higher than the most recent estimates of prevalence of CSHCN in those states from the National Survey of Children with Special Health Care Needs (12%, 13%, and 15%, respectively).<sup>41</sup> Interestingly, the prevalence of CSHCN in SCHIP was as high in Florida as in New York, although Florida has a carve-out program for CSHCN (CMS) that enrolls children with the most severe special health care needs. One explanation may be that few children with mental health conditions are admitted to CMS, because enrollment for children with such conditions is limited to 300 children statewide. Children with mild special needs (such as asthma) and most children with mental health conditions remain enrolled in SCHIP.

Other than being more likely to live in single-family households, demographic characteristics of CSHCN closely resembled those of children who did not screen positive for special needs. Confirming our second hypothesis, compared with children without special needs, CSHCN seemed to be somewhat more connected to the health care system before enrolling in SCHIP with respect to prior insurance, USC, and health care visits. This greater connection with the health care system may have been because of the poorer health status of CSHCN.

A higher proportion of SCHIP enrollees from New York and Florida were uninsured for the entire year before SCHIP, and a higher proportion in Kansas than the other study states had Medicaid as prior insurance. It is possible that the established nature of the New York and Florida programs accounts for the former finding in that the earlier SCHIP initiatives may have already enrolled children who were unin-

sured for short periods. The reasons for loss of prior insurance seem to reflect the type of prior insurance. For example, in Kansas where more children had Medicaid previously, fewer parents noted cost issues as reasons for loss of their prior insurance.

In support of the third hypothesis, the level of unmet health care needs of CSHCN on enrollment was high in all 4 states. This suggests that even as programs such as SCHIP mature, new enrollees will continue to have high levels of risk. In fact, both the CSHCN and children without special needs in the 2 states with mature programs were more likely than children in the 2 states with newer programs to have been uninsured for the entire year before SCHIP, underscoring the potential for unfulfilled health care needs among this population as well as the continuing need for long-term health insurance programs that cover all eligible children.

It is notable that the CSHCN population was generally similar to those without special needs on many access measures, and that the reported health status of most CSHCN was quite good. This suggests that the CSHCN screener identifies a broad spectrum of children and could not be used by SCHIP to focus exclusively on the most severely ill children. Also, many children who were not identified by the CSHCN screener still had unmet health care needs and fair or poor health. Thus, for the SCHIP population, the CSHCN screener does help to identify a group of at-risk children who merit extra attention from health care programs to ensure that their needs are met and to monitor their quality of care, but many other children are also potentially at risk for adverse health outcomes.

Two overarching trends emerged across New York, Florida, and Kansas in comparing CSHCN to children without special needs. CSHCN were more connected with the health care system (more likely to be insured, higher USC, and greater utilization) before SCHIP than children without special needs but nevertheless had more unmet health care needs (most commonly mental health, specialty care, and prescription medications). These trends could be detected despite the fact that the demographics of the children studied varied among the states (eg, the Florida study focused on adolescents, the New York sample had more black and Hispanic children, and the Kansas population was more rural). These findings suggest that SCHIP can work with existing health providers and networks to improve the health care delivery for CSHCN.

### **Policy Implications For SCHIP**

These findings have policy implications for SCHIP directors, policy makers, and child health experts regarding 1) SCHIP benefit design and payment systems, 2) financing, 3) coordination of care, and 4) monitoring and improving the quality of care for CSHCN. Some policy implications depend on the state context, and there are some statewide differences in SCHIP with respect to CSHCN (as described previously). Despite these differences, the overall findings across states were similar for many measures such as the prevalence of CSHCN (17–25%), the portion of CSHCN in fair/poor health (14–21%), the income and employment-related demographic characteristics of CSHCN, the portion having a USC, and the use of health care before SCHIP.

#### *Benefits and Program Design*

In most states, the needs of CSHCN were not actively considered when policy makers debated the design of separate SCHIP models, although some states did make special provisions for CSHCN.<sup>42</sup> Perhaps policy makers envisioned that SCHIP would enroll a relatively healthy population of children while children with special needs would enroll in Medicaid or special programs tailored to that population. In fact, an early qualitative study involving key informant interviews of SCHIP leaders in 5 states found “one issue that is particularly vexing to state officials and observers is the low number of children identified in their SCHIP as having special health care needs.”<sup>43</sup> The authors and key informants wondered whether causes for low enrollment of CSHCN included unsuccessful outreach to this population, the early stage of SCHIP, or perhaps that CSHCN were less likely to be uninsured. In contrast, SCHIP in our 4 states enrolled a population of children who, rather than being healthier than the general population, have more CSHCN than the general child population. The overall high level of unmet health care needs highlights the potential impact that SCHIP could have on the health of low-income children, especially CSHCN.

Separate, free-standing SCHIP programs including those in 3 of the 4 states evaluated in this study tend to offer more restricted benefit packages than Med-

icaid-expansion programs.<sup>44,45</sup> This is important with respect to CSHCN. We found that CSHCN had more unmet health care needs than other children, and prior studies have noted that many CSHCN require more specialty and ancillary services than their healthy counterparts.<sup>21–30</sup> For CSHCN, the benefit package design is critical.<sup>46</sup> This is particularly important for states that do not have carve-out programs for CSHCN or aggressive referral systems to Title V Maternal and Child Health Services programs and other wrap-around services that enable CSHCN with the most severe disabilities to receive expanded services. It may also have relevance to the consideration of copayments as a means of reducing state costs for SCHIP, because copayments can inhibit the receipt of health care, particularly for low-income families.<sup>2,21</sup>

A continuing challenge for states when designing SCHIP programs and benefits is to consider and distinguish children who may have more mild conditions from those with more serious conditions and health needs. Some children with more mild conditions may not require the full array of services typically found in a Medicaid benefit package. Nonetheless, a lower proportion but overall large number of children who did not screen in as CSHCN also had unmet health care needs before SCHIP, suggesting that SCHIP has potential to improve health care for the general population as well as for CSHCN.

#### *Financing*

The high utilization rates and unmet needs before SCHIP suggest that utilization of services by CSHCN during SCHIP will be substantial, resulting in higher costs than for children without special needs. Programs may need to consider different financing mechanisms for at least some of the CSHCN with the most severe conditions. These include risk-adjustment strategies,<sup>47–49</sup> high-risk pools,<sup>50,51</sup> reinsurance mechanisms,<sup>52,53</sup> and improved compensation of primary care practitioners (medical homes) for case management of CSHCN.

#### *Coordination of Care*

Coordination of care can occur at several levels, starting with the application process. Because many CSHCN enrolled in SCHIP and states have other programs that specifically serve CSHCN such as Title V Maternal and Child Health Services programs,<sup>54</sup> Supplemental Security Income,<sup>55</sup> or home- and community-based services waivers,<sup>56</sup> stronger ties between SCHIP, Medicaid programs, and these other programs could enhance the identification of CSHCN and the monitoring of their level of care.<sup>57</sup> Specific examples of coordination at this level include the use of joint application forms and single application processes to multiple programs, automatic referrals from one program to another, and joint care coordination.

In addition, health plans could expand their specialty provider network based on providers' participation in the other programs and offer resources for coordination of care by health care providers. Furthermore, because the USC for many children en-

rolled in SCHIP was a community health center, it is important to promote connections between these providers and specialty providers, particularly for CSHCN. Our finding that many CSHCN changed their primary care providers after enrollment into SCHIP highlights the importance of provider networks. Continuity of care is critical for CSHCN because of their chronic conditions.<sup>58,59</sup> Additional study is needed to determine why so many children changed providers, to assess whether limited provider panels may have accounted for these findings, and to evaluate the impact of changing providers on quality of care for CSHCN. Our study suggests that the adequacy of specialty provider networks including mental health care also needs to be evaluated within SCHIP. Although studies have found that access to specialists has been one of the more common barriers to CSHCN in managed care settings,<sup>25,60–64</sup> little is known about access to specialty care within SCHIP.

### *Monitoring Quality*

The high prevalence of CSHCN in SCHIP and the high rates of change in USC after enrollment in SCHIP both point to the importance of monitoring the quality of care for this vulnerable population. An important first step is the use of a systematic means to identify the population of CSHCN within SCHIP. One potential strategy is for SCHIP to adopt the CSHCN and/or other screening instruments for families to complete at enrollment and recertification. The next step would be to monitor their level of care by using routine assessment-of-health measures that are critical to CSHCN<sup>65–67</sup> or children with specific diseases.<sup>68</sup> Our results of quality of care show high marks for the quality of providers' care even before SCHIP. These quality measures did not distinguish CSHCN from other children, and it is possible that quality measures more specific to CSHCN would be useful for this subgroup. For example, performance measures focused on mental health, specialty, and dental care may be useful in particular for CSHCN, and these were all areas of high unmet needs in the current study.

### **Strengths and Limitations**

This study has several strengths. The results represent early findings from SCHIP in several states representing >25% of all SCHIP enrollees in the nation. Although there are some variations in aspects of these programs, the similarities across states in prevalence of CSHCN, demographic characteristics, and prior health care experiences of CSHCN suggests that the findings may be applicable beyond single states. These results will be critical to determining the impact of SCHIP on the health care of CSHCN, because the quality of health care during SCHIP represents a combination of the performance of plans and providers as well as sociodemographic features and prior unmet needs of patients.

Several study limitations must also be noted. Large-scale, multistate comparisons would be needed to assess whether findings from the study's 4

states are applicable to other states. Unfortunately, national surveys including the National Survey of Children with Special Needs often cannot distinguish the SCHIP population or else have a limited number of SCHIP subjects. However, comparisons of the study findings to aggregate results from national-level studies that can identify the SCHIP population would be helpful.

Second, several questions varied somewhat across states, and the study populations varied in that the Florida sample included only adolescents and the Indiana sample included only CSHCN. The major study objective was to compare CSHCN versus other children within the same states and differences in questions and populations-limit comparisons across the states. Third, some of the differences between CSHCN and children without special needs may not be because of the special needs but to other confounding factors that were not accounted for by multivariate analyses. Fourth, no screening tool is perfect, and the CSHCN screener may have misclassified some children into or not into the CSHCN group.<sup>13,18</sup> Fifth, these findings are from parent reports and subject to inaccuracies. The questions on utilization of care may be most subject to errors in reporting, although some evidence exists that parents accurately recall key visits to health care professionals such as ED visits and specialty visits.<sup>69,70</sup> Moreover, because the same measures were used to compare CSHCN versus children without special needs, inaccuracies in parental recall may not translate to a bias toward either higher or lower utilization for CSHCN versus children without special needs.

### **CONCLUSIONS**

We conclude that SCHIP in these states has a similar proportion of CSHCN as the general pediatric population, and although CSHCN were better connected with the health care system before SCHIP, they nevertheless had substantial unmet health care needs at enrollment. A measure of SCHIP's success will be the degree to which the program effectively serves CSHCN. Strategies that states might use to serve CSHCN more effectively might include careful attention to the benefit structure of SCHIP, innovative methods of financing of this high-cost group of children, coordination of care and services, and regular assessment of the quality of care for CSHCN.

### **ACKNOWLEDGMENTS**

This work, funded by 4 cooperative agreements from the Agency for Health Care Research and Quality (FL HS10465, KS HS10536, IN HS10453, and NY HS10450), is part of CHIRI, which is cofunded by the Agency for Health Care Research and Quality, the David and Lucile Packard Foundation, and the Health Resources and Services Administration. Additional support was provided for the Kansas project by the Kansas Health Foundation, the United Methodist Health Ministry Fund, and the Prime Health Foundation; and for the New York project by the New York State Department of Health.

We gratefully acknowledge collaboration of Robert St. Peter (Child Health Insurance Research Initiative Principal Investigator in Kansas) and Karen VanLandeghem. Thanks are also due to Cindy Mann and Steve Berman, who conscientiously commented on an earlier draft of this article.

## REFERENCES

- Newacheck PW, Halfon N, Inkelas M. Monitoring expanded health insurance for children: challenges and opportunities [commentary]. *Pediatrics*. 2000;105:1004–1007
- Szilagyi PG. Children with special health care needs in publicly funded health insurance programs. *Future Child*. 2003;13:137–152
- McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998;102:137–140
- Bethel C, Read D. *Child and Adolescent Health Initiative. Living With Illness Screener and Supplemental Survey Module: Description and Summary of Development and Testing*. Portland, OR: Foundation for Accountability; 1999
- Stein REK, Westbrook LE, Bauman LJ. The questionnaire for identifying children with chronic conditions: a measure based on a noncategorical approach. *Pediatrics*. 1997;99:513–521
- Stein RE, Silver EJ, Bauman LJ. Shortening the questionnaire for identifying children with chronic conditions: what is the consequence? *Pediatrics*. 2001;107(4). Available at: <http://www.pediatrics.org/cgi/content/full/107/4/e61>
- Carmen KL, Short PF, Farlet DO, Schnaier JA, Elliott DB, Gallagher PM. Epilogue: early lessons from CAHPS demonstrations and evaluations. *Med Care* 1997;37 (3 suppl):MS97–MS105
- Bethell CD, Read D, Neff J, et al. Comparison of the children with special health care needs screener to the questionnaire for identifying children with chronic conditions—revised. *Ambul Pediatr*. 2000;2:49–57
- Bethell CD, Read D, Stein RE, Blumberg SJ, Wells N, Newacheck PW. Identifying children with special health care needs: development and evaluation of a short screening instrument. *Ambul Pediatr*. 2000;2:38–48
- Stein REK, Silver EJ. Operationalizing a conceptually based noncategorical definition: a first look at US children with chronic conditions. *Arch Pediatr Adolesc Med*. 1999;153:68–74
- Newacheck PW, Strickland B, Shonkoff JP, et al. An epidemiologic profile of children with special health care needs. *Pediatrics*. 1998;102:117–123
- Centers for Disease Control, National Center for Health Statistics. SLAITS (State and Local Area Integrated Telephone Survey): the Children With Special Health Care Needs Module. Available at: <http://www.cdc.gov/nchs/about/major/slaits/cshcn.htm>. Accessed June 4, 2002
- van Dyck PC, McPherson M, Strickland BB, et al. The national survey of children with special health care needs. *Ambul Pediatr*. 2002;2:29–37
- The Health Plan Employer Data and Information Set. Available at: <http://www.ncqa.org/Programs/HEDIS/index.htm>. Accessed December 28, 2001
- Measuring Quality for Children with Special Health Care Needs CAHPS (Consumer Assessment of Health Plans) Survey. Available at: <http://www.familyvoices.org/publist.html>. Accessed December 31, 2001
- Fox H, Graham R, McManus M, et al. An analysis of States' CHIP policies with special health care needs. Washington, DC: Maternal and Child Health Policy Research Center; 1999
- Fox HB, McManus MA, Austrian JS. *An Analysis of Safeguards for Children With Special Needs in States' Medicaid Managed Care Contracts, 1999. Issue Brief Number 4, The Medicaid Managed Care Trends Project*. Washington, DC: Maternal and Child Health Policy Research Center; 2000
- Shenkman EA, Wegener DH. *Strategies for Identifying Children With Special Health Care Needs*. Gainesville, FL: Institute for Child Health Policy; 2000
- American Academy of Pediatrics. Legislative and regulatory issue: Maternal and Child Health Block Grant. Washington, DC. Available at: <http://www.aap.org/advocacy/Washing/maternal.htm>. Accessed December 8, 2001
- Newacheck PW, McManus M, Fox HB, Hung Y-Y, Halfon N. Access to health care for children with special health care needs. *Pediatrics*. 2000;105:760–766
- Stein REK. Challenges in long-term health care for children. *Ambul Pediatr*. 2001;1:280–288
- Newacheck PW, Hughes D, Stoddard JJ, Halfon N. Children with chronic illness: prevalence, severity, and impact. *Am J Public Health*. 1994;93:497–500
- Leonard B, Burst JD, Sapienza JJ. Financial and time costs to parents of severely disabled children. *Public Health Rep*. 1992;107:302–312
- Edevmonds M, Coye MJ, eds. (Institute of Medicine). *America's Children*. Washington, DC: National Academy Press; 1998
- Fox HB, Wicks LB, Newacheck PW. Health maintenance organizations and children with special health needs. A suitable match? *Am J Dis Child*. 1993;147:546–552
- Hill I, Schwalberg R, Zimmerman B, Tilson W. Achieving service integration for children with special health care needs: an assessment of alternative Medicaid managed care models. Available at: <http://www.jhsph.edu/centers/cshcn/volume1.pdf>. Accessed December 28, 2001
- Shatin D, Levin R, Ireys HT, Haller V. Health care utilization by children with chronic illnesses: a comparison of Medicaid and employer-insured managed care. *Pediatrics*. 1998;102(4). Available at: <http://www.pediatrics.org/cgi/content/full/102/4/e44>
- Liptak GS, Burns CM, Davidson PW, McAnarney ER. Effects of providing comprehensive ambulatory services to children with chronic conditions. *Arch Pediatr Adolesc Med*. 1998;152:1003–1008
- Thomas SD, Whitman S. Asthma hospitalizations and mortality in Chicago: an epidemiologic overview. *Chest*. 1999;116(suppl):1355–1415
- Szilagyi PG, Schor EL. The health of children. *Health Serv Res* 1998;33:1001–1039
- Dick A, Szilagyi PG, Shone LP, Klein JD, Yu H, Zwanziger J. The evolution of State Children's Health Insurance Program (SCHIP) in New York: changing characteristics of the population. *Pediatrics*. 2003;112(6). Available at: <http://www.pediatrics.org/cgi/content/full/112/6/e542>
- Shenkman E, Col J, Youngblade L, Nackashi J. Adolescent preventive care experiences before entry into State Children's Health Insurance Program (SCHIP) or Medicaid. *Pediatrics*. 2003;112(6). Available at: <http://www.pediatrics.org/cgi/content/full/112/6/e533>
- Trafton S, Shone LP, Zwanziger J, et al. Evolution of a children's health insurance program: lessons from New York State's Child Health Plus. *Pediatrics*. 2000;105:692–696
- Szilagyi PG, Zwanziger J, Rodewald LE, et al. Evaluation of a state health insurance program for low-income children: implications for state child health insurance programs. *Pediatrics*. 2000;105:363–371
- State Children's Health Insurance Program Approved Plan Files. Available at: <http://www.cms.hhs.gov/schip/chpa-map.asp>. Accessed July 2, 2002
- Centers for Medicare and Medicaid Services. The State Children's Health Insurance Program Annual Enrollment Report. Federal Fiscal Year 2001: October 1 2000–September 30, 2001. Available at: <http://www.cms.hhs.gov/schip/schip01.pdf>. Accessed June 25, 2002
- Shenkman E, Steingraber H, Bono C. Florida KidCare Program evaluation report, January 2002. Available at: <http://www.ichp.edu/FloridaKidCare/2001-2002Reports/2001-2002FinalKC3rdYear.pdf>. Accessed May 29, 2002
- St Peter R, Allison A, LaClair BJ. Technical appendix B: Kansas survey methods. *Pediatrics*. 2003;112(6). Available at: <http://www.pediatrics.org/cgi/content/full/112/6/e556>
- Swigonski N. Technical appendix C: Indiana survey methods. *Pediatrics*. 2003;112(6). Available at: <http://www.pediatrics.org/cgi/content/full/112/6/e558>
- The Child and Adolescent Health Measurement Initiative (CAHMI). Children with special health care needs: the CSHCN screener. Available at: <http://www.facct.org/cahmiweb/chronic/lwihome.htm>. Accessed June 25, 2002
- Blumberg SJ, Olson L, Frankel M, et al. Design and operation of the National Survey of Children with Special Health Care Needs, 2001. *Vital Health Stat 1*. 2003;(41):1–136
- Hill I, Lutzky AW, Schwalberg R. Are we responding to their needs? States' early experiences serving children with special health care needs under SCHIP. 2001. Available at: <http://newfederalism.urban.org/html/op48/occa48.html#state>. Accessed March 3, 2003
- Schwalberg R, Mathis SA, Hill I. New opportunities, new approaches: serving children with special health care needs under SCHIP; Volume 1: Synthesis of study results. Available at: <http://www.jhsph.edu/centers/cshcn/volume1.pdf>. Accessed March 3, 2003
- American Academy of Pediatrics, Committee on Child Health Financing. Implementation principles and strategies for the State Children's Health Insurance Program. *Pediatrics*. 2001;107:1214–1220
- Fox HB, Limb SJ, McManus MA. Resource Paper: SCHIP innovations for children with special needs in managed care. Center for Healthcare Strategies, Inc. 2003. Available at: <http://www.chcs.org/publications/pdf/ips/schip.pdf>. Accessed March 14, 2003
- Perrin J. Health services research for children with disabilities. *Milbank Q*. 2002;80:303–324
- Shenkman EA, Breiner JR. *Characteristics of Risk Adjustment Systems*. Gainesville, FL: Institute for Child Health Policy; 2001
- Iezzoni LI. The risks of risk adjustment. *J Am Med Assoc*. 1997;278:1600–1607
- Neff JM, Sharp VL, Muldoon J, Graham J, Popalisky J, Gay JC. Identifying and classifying children with chronic conditions using adminis-

- trative data with the Clinical Risk Group Classification System. *Ambul Pediatr*. 2002;2:71-79
50. Enthoven A, Kronick R. A consumer-choice health plan for the 1990s. Universal health insurance in a system designed to promote quality and economy (2). *N Engl J Med*. 1989;320:94-101
  51. Fritz DL. Options for providing health care for the uninsured: opportunities for managed care. *J Health Soc Policy*. 1989;1:61-73
  52. Goldfield N. Case mix, risk adjustment, reinsurance, and health reform. *Manag Care Q*. 1994;2:iv-vii
  53. Anderson GF, Weller WE. Methods of reducing the financial risk of physicians under capitation. *Arch Family Med*. 1999;8:149-155
  54. American Academy of Pediatrics. MCHB medical home & integrated services grant initiatives. Available at: <http://www.medicalhomeinfo.org/grant/mchb.html>. Accessed October 29, 2003
  55. American Academy of Pediatrics, Committee on Children with Disabilities. The continued importance of Supplemental Security Income (SSI) for children and adolescents with disabilities. *Pediatrics*. 2001;107:790-793
  56. Family Voices. Waivers: the Katie Beckett waivers and the 1115 waivers. Available at: <http://www.familyvoices.org/Information/ma-kbw.htm>. Accessed December 8, 2001
  57. Agency for Healthcare Research and Quality User Liaison Program. Coordinating publicly funded healthcare coverage for children: research report. Available at: <http://www.ahrp.gov/news/ulp/making/ulplink.htm>. Accessed June 4, 2002
  58. American Academy of Pediatrics. Medical home initiatives for children with special needs. Available at: <http://www.medicalhomeinfo.org/index.html>. Accessed December 4, 2001
  59. American Academy of Pediatrics. What's a medical home? Available at: [http://www.medicalhomeinfo.org/resources/gen\\_med\\_materials/MH%20and%20DOCP%20Fact%20Sheet.pdf](http://www.medicalhomeinfo.org/resources/gen_med_materials/MH%20and%20DOCP%20Fact%20Sheet.pdf). Accessed May 14, 2002
  60. Horowitz SM, Stein REK. Health maintenance organizations versus indemnity insurance for children with chronic illnesses. *Am J Dis Child*. 1990;144:581-586
  61. Cartland JD, Yudkowsky BK. Barriers to pediatric referral in managed care systems. *Pediatrics*. 1992;89:183-192
  62. Davidson SM, Manheim LM, Werner SM, Hohlen MM, Yudkowsky BK, Fleming GV. Prepayment with office-based physicians in publicly funded programs: results from the children's Medicaid program. *Pediatrics*. 1992;89:761-767
  63. Freund DA, Lewit E. Managed health care for children and pregnant women: promises and pitfalls. *Future Child*. 1993;3:92-123
  64. Reid RJ, Hurtado MP, Starfield B. Managed care, primary care, and quality for children. *Curr Opin Pediatr*. 1996;8:164-170
  65. Newacheck PW, Stein RE, Walker DK, Gortmaker SL, Kuhlthau K, Perrin JM. Monitoring and evaluating managed care for children with chronic illnesses and disabilities. *Pediatrics*. 1996;98:952-958
  66. Kuhlthau K, Walker DK, Perrin JM, et al. Assessing managed care for children with chronic conditions. *Health Aff*. 1998;17:42-52
  67. Consumer Assessment of Health Plans (CAHPS). Children with special health care needs. Available at: <http://www.facct.org/cahmiweb/chronic/CAHPS/lwicahps.htm>. Accessed December 31, 2001. Also see <http://www.cdc.gov/nchs/about/major/slaits/cshcn.htm>. Accessed June 18, 2002
  68. Perrin JM, Kuhlthau K, Walker DK, et al. Monitoring health care for children with chronic conditions in a managed care environment. *Matern Child Health J*. 1997;1:15-23
  69. Harel Y, Overpeck MD, Jones DH, et al. The effects of recall on estimating annual nonfatal injury rates for children and adolescents. *Am J Public Health*. 1994;84:599-605
  70. Pless CE, Pless IB. How well they remember. The accuracy of parent reports. *Arch Pediatr Adolesc Med*. 1995;149:553-558