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# Race and Ethnicity and the Identification of Special Needs Children

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*Increasingly, Medicaid and Title XXI Programs are using survey-based approaches to identify children with special health care needs (CSHCN) for quality assurance monitoring and program referrals. However, little work has been done examining how well instruments, like the Questionnaire for Identifying Children with Chronic Conditions and the CSHCN Screener, identify CSHCN among black and Hispanic families. Differences in item interpretation and in response styles could influence the identification of CSHCN from these groups. Our results suggest that children who are black or Hispanic with special health care needs may be underidentified relative to white or non-Hispanic children using currently available survey tools.*

## INTRODUCTION

In January 2001, CMS sent a Report to Congress detailing various safeguards that States and other entities should enact to ensure that individuals with special health care needs enrolled in Medicaid managed care receive appropriate health care services (Health Care Financing Administration, 2000). This report was mandated as part of the Balanced Budget Act of 1997, which established beneficiary protections for spe-

cial populations, including CSHCN. The first step in monitoring and ensuring the quality of care for CSHCN is to identify them. In fact, CMS now requires States to have mechanisms in place to identify CSHCN who are enrolled on a mandatory basis in Medicaid managed care. CMS has further recommended that State Medicaid agencies be required to report the number of enrollees with special health care needs in their Medicaid managed care programs.

Increasingly, Medicaid and Title XXI, State Children's Health Insurance Programs (SCHIP), are using survey-based approaches to identify CSHCN (Kaye, Curtis, and Booth, 2000; Shenkman, Steingraber, and Bono, 2000). Three well-tested survey measures are available to identify CSHCN: the (1) Questionnaire for Identifying Children with Chronic Conditions (QuICCC), (2) shorter, revised version of the QuICCC called the QuICCC-R, and (3) CSHCN Screener (Stein, Westbrook, and Bauman, 1997; Bethell and Read, 1999). The screening instruments contain a common core of questions about medication use, health care use, functional limitations, and the duration of the condition. We selected these three instruments for use in this study because they are being used in their entirety or in part in several State programs to identify children for referral to specialized programs such as State Title V CSHCN Programs or for care coordination purposes.

Previous studies (Stein, Westbrook, and Bauman, 1997) conducted with these instruments have examined whether CSHCN using these instruments also have formal

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diagnoses indicating the presence of chronic conditions. In addition, investigators have focused on shortening the length of the instruments, while retaining their ability to identify the children. However, little work has been done examining how well these instruments identify CSHCN among various racial and ethnic groups. For each instrument, the respondent, who is usually the child's parent, is expected to answer the questions based on his or her understanding of the child's functioning and health care use and needs. However, differences in item interpretation and in response styles could influence the identification of CSHCN who also are from minority backgrounds (Morales, Reise, and Hays, 2000). Parents' perception of their children's health appear to be influenced by non-health related factors such as family income and cultural orientation (Arcia, 1998). More studies are needed to determine how instruments designed to identify CSHCN, such as the QuiCCC and the CSHCN Screener, function with respondents from diverse racial and cultural groups.

The primary objective of this study was to examine the influence of health-related, race, and ethnicity variables on the odds that a child would be identified as having a special health care need using the QuiCCC, the QuiCCC-R and the CSHCN Screener. The health-related variables include the child's health status, whether the child had a formal diagnosis indicating a special need, and the child's health care use rate. In this analysis the racial and ethnic groups included children who were white, black, of mixed race, Hispanics, and non-Hispanics. Because studies have demonstrated that variations attributed to race and ethnicity are often due to variations in income or education, family income and respondent education were included in the analyses (Kingston and Smith, 1997).

To address this objective we conducted two primary analyses:

- First, we examined whether any differences in children being identified as CSHCN using the screening instruments might be attributed to differences in children having formal diagnoses indicating the presence of a special need, as opposed to racial and ethnic variations in interpretation of the questions on the screening instruments. This analysis was conducted in two steps. To obtain a formal diagnosis of a special health care need, the child had to have used the health care system at least once. Therefore, we began by estimating the relationship between the child's health status and sociodemographic characteristics and the odds that he or she would have used the health care system at least once. Then for those children who used the health care system at least once, we examined the relationship between the child's health status and sociodemographic characteristics and the odds that he or she would have a formal diagnosis indicating the presence of a special health care need.
- Second, we examined the relationship between the child's health status and sociodemographic variables and the odds that the child would be identified as having a special health care need using each of the three screening instruments—the QuiCCC, the QuiCCC-R, and the CSHCN Screener.

## BACKGROUND

Identifying (CSHCN) for the purposes of coordinating their care, making referrals to needed programs and services, and monitoring the quality of their health care is essential. The QuiCCC, the QuiCCC-R, and the CSHCN Screener are three survey-based approaches for identifying CSHCN.

QuICCC and QuICCC-R) are designed to identify those children who have: (1) a biological, psychological, or cognitive disorder, (2) duration of at least 12 months, and (3) consequences of the disorder such as functional limitations, reliance on compensatory mechanisms or assistance, or service use beyond that which is considered routine (Stein, Westbrook, and Bauman, 1997). The QuICCC contains three dimensions: (1) functional limitations, (2) dependence on compensatory mechanisms or assistance, and (3) service use or need beyond routine care. The child is considered to have a special health care need if they have any of the preceding functional consequences.

The 39-item QuICCC has been tested with different populations of children and identifies children with conditions traditionally thought of as representing special health care needs. Moreover, testing has demonstrated the importance of the different components of the QuICCC (i.e., functional limitations, compensatory dependence, and service use or need components) in identifying varying groups of children. The QuICCC-R contains 16 items that are a subset of the QuICCC.

The CSHCN Screener contains five items that address whether the child (1) has activity limitations when compared with other children of his or her age, (2) needs or uses medications, (3) needs or uses specialized therapies such as physical therapy and others, (4) has an above routine need or use for medical, mental health, or educational services, or (5) needs or gets treatment or counseling for an emotional, behavioral, or developmental problem. For any category with an affirmative response, the parent is then asked if this is due to a medical, behavioral, or other health condition and whether that condition has lasted or is expected to last at least 12 months. The child is considered to have

a special need if the parent responds affirmatively to any of the categories (Bethell and Read, 1999). The CSHCN Screener has been tested on several populations of children and the testing supports the dimensions included in the instrument.

## METHODS

### Study Questions

The purpose of the study was to examine the influence of health-related, race, and ethnicity variables on the odds that a child would be identified as having a special health care need using the QuiCCC, the QuICCC-R, and the CSHCN Screener. However, before examining those relationships, other analyses had to be conducted. It is possible that differences in children being identified as CSHCN using any of the screening instruments could be attributed to differences in the children actually having diagnoses indicating the presence of a special health care need as opposed to racial and ethnic variations in interpretation of the questions on the screening instruments. We could only identify a formal diagnosis indicating the child had a special health care need in our claims and encounter files if the children used the health care system at least once. Therefore, we began our analyses examining whether the children used the health care system at least once and for those using the health care system at least once whether they had any diagnoses indicating the presence of a special health care need. The following study questions guided this phase of the analysis:

- What is the relationship between the child's sociodemographic characteristics and health status and the odds of using health care services at least once?
- For those children using the health care system, what is the relationship between

the child's sociodemographic characteristics and health status and the odds of having a formal diagnosis indicating the presence of a special health care need?

The following study question guided our analyses examining whether there were any racial or ethnic variations noted in the odds of a child being identified with a special health care need using any of the screening instruments: What is the relationship between the child's sociodemographic and health characteristics and the odds of a child being identified with a special health care need using the QuICCC, the QuICCC-R or the CSHCN Screener?

### **Study Setting and Sample Selection**

This study was conducted with families whose children were enrolled in the Florida Healthy Kids Program. The Healthy Kids Program is the largest component of Florida's Title XXI State Children's Health Insurance Program initiative with a current enrollment of over 150,000 children. The program is available to children between the ages of 5 and 19. Those below 200 percent of the Federal poverty level receive subsidized health insurance premiums. The benefit package is comprehensive and covers preventive care with no copayment, and other outpatient care, inpatient care, rehabilitative services, mental health care, and emergency services with minimal copayments. Children with special health care needs enrolled in the Healthy Kids Program do not have conditions that are severe enough to meet the medical eligibility of Florida's Title V CSHN Program.

After institutional review board approval was obtained from The University of Florida, Health Science Center, a random sample of 2,400 families whose children were enrolled in the Healthy Kids Program during October 1, 1998-September 30, 1999

(out of 121,089 enrollees) was selected to participate in our study. Of these families, 21 percent could not be located with the available contact information. Nine percent of those located refused to participate in the study for a final sample of 1,724 children. Those that could not be located did not differ significantly from those located on family income, the child's age or sex, months enrolled in the program, or health care use rates (data not shown). The families were asked to participate in a telephone survey about their children's health. Respondents were selected by asking to speak to the person in the household who knew the most about the child's health. In 97 percent of the cases, the respondent was the child's mother. Nine percent of the interviews were completed in Spanish.

### **Data Sources**

Three data sources were used for this study. First, the Healthy Kids Corporation provided child-specific enrollment information containing the child's enrolled program months, age, sex, and family income. Second, each health plan provided child-specific health care encounter data including *Physician's Current Procedural Terminology* codes and *International Classification of Diseases, 9th Revision, Clinical Modification* (ICD-9-CM) codes. Encounter data from July 1, 1999-June 2000 were used in the analysis.

Third, the survey data obtained from each respondent were linked to the enrollment and encounter files. The telephone surveys were conducted from September 1999-November 1999 and included the following: a demographic section including race, ethnicity, and respondent education; QuICCC; QuICCC-R; and the CSHCN Screener. In addition, families were asked to rate their children's health (excellent, very good, good, fair, or poor).

Each screening instrument has specific and similar instructions for scoring. For all three instruments, the questions capture three domains related to children's health: limitations in functioning, dependency on compensatory devices, and service use or need that is higher than would be expected for other children of the same age. Regardless of the particular screening instrument, the majority of questions have a two-question followup sequence designed to identify whether the particular health care concern is related to a physical or emotional condition and the actual or expected duration of that condition. For example, each screening instrument has a question asking whether the child needs or uses medications prescribed by a doctor. If so, there are two followup questions that ask if the medicine is needed because of any medical, behavioral, or other health condition, and if so, if that condition has lasted or is expected to last for 12 months or longer. A child is considered to have a special health care need if his or her parent responds affirmatively to one of the primary questions and the associated followup questions in any of the three domains: limitations in functioning, dependency on compensatory devices, and service use or need that is higher than would be expected for other children of the same age.

The University of Florida Telephone Survey Research Center conducted the interviews using a computer-assisted telephone interviewing system. Informed consent was contained from the respondent in the household who was 18 years of age or older and who knew the most about the child's health care.

## **Predictor Variables**

To address the first and second study questions the child's health status and sociodemographic characteristics were used as predictor variables. The health sta-

tus variable was the parental report of the child's overall health status rated as excellent, very good, good, fair, and poor. Because few children were reported to be in fair or poor health, these two categories were collapsed into one. The following demographic data were used: child's race, coded as white, black, or other; ethnicity (Hispanic or non-Hispanic); child's age; child's sex; respondent education; family income; and the number of months the child was enrolled in the program.

The health status variable was selected for inclusion in this analysis because prior research has demonstrated that parents' perceptions of their children's health are related to health care use and to the presence of diagnoses indicating special health care needs (McGee et al., 1999). Because other studies have demonstrated that variations attributed to race and ethnicity are often due to variations in income or education, family income and respondent education were included in the analyses (Kingston and Smith, 1997).

To address the third study question the following predictor variables were used: the child's health status as measured by parental report and the previously described sociodemographic variables. In addition, we constructed a dummy variable to indicate whether the child had an ICD-9-CM code in the claims and encounter data that would indicate the presence of a special health care need (1 = No; 0 = Yes).

We expected that children in poorer health and those who had formal diagnoses indicating special health care needs would have higher odds of being identified with special health care needs using the screening tools than children without such characteristics. The construction of the variable from encounter data indicating whether the child had an ICD-9-CM code indicating the presence of a special health care need is explained as follows.

Children were identified as having a special health care need using the clinical risk groups (CRGs). CRGs is a population-based classification system that uses ICD-9-CM codes to characterize individuals with congenital and chronic health conditions or significant acute conditions for the purposes of risk adjustment, generation of prevalence rates, physician profiling, and provision of quality assurance tracking. The system has undergone significant development and testing (Muldoon, Neff, and Gay, 1997). Each enrollee is classified into one of nine hierarchically defined core health status groups: healthy (includes non-users); significant acute; minor chronic; multiple minor chronic pairs; single dominant or moderate chronic; multiple significant chronic pairs; chronic triplets; catastrophic; and metastatic malignancy. Most conditions are classified only if there have been at least two outpatient encounters for that condition, with different service dates. A few conditions require only one health care encounter such as Down's Syndrome and blindness. Children assigned to the following categories were considered to have special health care needs: single dominant or moderate chronic conditions; multiple significant chronic pairs of conditions; chronic triplets of conditions; catastrophic conditions; and metastatic malignancy.

### **Outcome Variables**

Outcome variables were whether the child: (1) used the health care system at least once, (2) had a formal diagnosis indicating a special health care need (based on diagnoses found in the claims and encounter data and as categorized by the CRGs), and (3) was identified as having a

special need care need using each of the three screening instruments. Each instrument was scored according to the instructions provided by the developers.

### **Analyses Conducted**

Descriptive statistics were used to characterize the children participating in the study. Chi-square statistics were used to initially examine any differences by race or ethnicity in the: (1) percentage of children using the health care system, (2) percentage of children with a formal diagnosis indicating a special health care need, (3) parent's perceptions of the children's health status, and (4) percentage of children identified as having a special health care need by the QuICCC, the QuICCC-R, and the CSHCN Screener.

In addition, we conducted a logistic regression analysis to assess the relationship between the child's health and sociodemographic variables and the odds that the child used the health care system at least once. For those children using the health care system at least once, we then examined the odds that they would have a diagnosis indicating a special health care need. We also estimated three logistic regression equations examining the relationship between the child's health and sociodemographic variables, and the odds that the child would be identified as having a special health care need, using each of the three instruments (the QuICCC, the QuICCC-R, and the CSHCN Screener). No problems with multicollinearity among the predictor variables were found. Interaction terms between race and all other predictor variables and ethnicity and all other predictor variables were not significant, therefore they were dropped from the models.

## RESULTS

### Descriptive Analyses

The majority of children were between the ages of 5 and 13 years (mean age of 11.0 years) (Table 1). Fifty-one percent were male. The majority of children were white (66 percent), 19 percent black, and 15 percent multiracial. Respondents who indicated that they were not members of any of the racial groups listed on the survey (i.e., white, black, Asian, etc.) were asked to describe their racial background. All of them indicated that they were of multiracial background. Less than 1 percent of respondents were Asian and these were excluded from any of the survey response rate calculations and analyses because there were so few of them. In terms of ethnicity, most were non-Hispanic (78 percent), while 22 percent were Hispanic. Family income averaged about \$19,000 annually. Children were enrolled on average 8 months out of the year studied. One-half the respondents had a high school diploma or less.

Seventy-seven percent of respondents indicated their children were in very good to excellent health. Seventy-two percent of the children had not used health care services during the time period studied. On average, across all children in the sample, the children had about five health care encounters annually (range: 0-20). The percentage of children identified as having special health care needs using the survey instruments ranged from 24 percent to 34 percent.

Table 2 contains a summary of the analyses examining the relationships between race and ethnicity and the children's (1) health care use, (2) diagnoses, and (3) identification as special needs children using the screening instruments. A significantly higher percentage of black or mul-

tiracial families perceived their children to be in poor to good health when compared with white families (32 percent and 28 percent respectively versus 20 percent;  $\chi^2 = 33.00$ ,  $p < 0.0001$ ). Similarly, a higher percentage of Hispanic families perceived their children to be in poor to good health when compared with non-Hispanic families (29 percent versus 22 percent;  $\chi^2 = 10.55$ ,  $p = 0.0321$ ). A significantly higher percentage of white children used the health care system at least once, when compared with black or multiracial children. For example 65 percent of the black children compared with 75 percent of the white children used the health care system at least once ( $\chi^2 = 12.27$ ,  $p = 0.0022$ ). The same pattern was seen when comparing Hispanic and non-Hispanic children. Sixty-two percent of Hispanic children used the health care system at least once compared with 71 percent of the non-Hispanic children ( $\chi^2 = 4.51$ ,  $p < 0.0037$ ).

Once the children used the health care system, there were no significant differences noted in the percentage of children who had a formal diagnosis indicating the presence of a special health care need based on race or ethnicity ( $\chi^2 = 4.74$ ,  $p = 0.0937$  and  $\chi^2 = 4.43$ ,  $p = 0.0822$ ). However, significant racial and ethnic differences were observed in the percentage of children identified as having special health care needs using the screening instruments. For example, 35 percent of the white children, 23 percent of the black children and 33 percent of the multiracial children were identified as having a special health care need using the QuICCC criteria ( $\chi^2 = 18.37$ ,  $p < 0.0001$ ). A similar pattern was observed for the QuICCC-R ( $\chi^2 = 17.00$ ,  $p = 0.0002$ ) and the CSHCN Screener ( $\chi^2 = 22.77$ ,  $p = 0.0001$ ). For children who were Hispanic 27 percent were identified as having a special health care need using the QuICCC compared with 34 percent of non-

**Table 1**  
**Sociodemographic and Health-Related Variables of Children Included in the Study<sup>1</sup>, by Response Rate**

Sociodemographic Variable	Response (N=1,724)
<b>Mean Age of Child<sup>2</sup></b>	
	Percent
<b>Sex</b>	
Male	51
Female	49
<b>Race</b>	
White	66
Black	19
Other	15
<b>Ethnicity</b>	
Hispanic	22
Non-Hispanic	78
<b>Family Income<sup>3</sup></b>	
Below 133 Percent FPL	68
133-150 Percent FPL	9
150-200 Percent FPL	18
200 Percent FPL or Above	5
<b>Months Enrolled<sup>4</sup></b>	
6 Months or Less	36
6 Months or More	64
<b>Respondent Education</b>	
Less than High School	11
High School Graduate	39
Technical/Trade School	34
College Graduate or Higher	16
<b>Health Status</b>	
Excellent	47
Very Good	30
Good	19
Fair	4
Poor	<1
<b>Health-Related Variable</b>	
Not Used the Health Care System	72
<b>Average Health Care Encounters Per Month<sup>5</sup></b>	
Formal Diagnosis Indicating a Special Health Care Need	12
<b>Identified with a Special Health Care Need</b>	
QuICCC	34
QuICCC-R	33
CSHCN Screener	24

<sup>1</sup>Included families whose children were enrolled in the Florida Healthy Kids Program during October 1, 1998-September 30, 1999 (a random sample of 2,400 out of 121,089 enrollees).

<sup>2</sup>(11.0±3.70.)

<sup>3</sup>(\$19,162±\$8,360.)

<sup>4</sup>(8.25±3.77.)

<sup>5</sup>(6.44±0.73.)

NOTES: (Mean±standard deviation.) Twenty-one percent of the families could not be located with available contact information, 9 percent refused to participate, for a final study sample of 1,724. FPL is Federal poverty level. QuICCC is Questionnaire for Identifying Children with Chronic Conditions. QuICCC-R is a shorter, revised version of QuICCC. CSHCN is children with special health needs.

SOURCE: University of Florida Telephone Survey Research Center computer-assisted interviewing, September 1999-November 1999.

**Table 2**  
**Summary Variable Results of Chi-Square Analyses, by Race and Ethnicity**

Variable	Race			Ethnicity	
	White	Black	Other	Non-Hispanic	Hispanic
	Percent				
<b>Health Status</b>					
Excellent	*49	*38	*46	*47	*45
Very Good	*31	*30	*26	*31	*26
Good	*17	*24	*23	*18	*24
Fair/Poor	*3	*8	*5	*4	*5
Used Health Care System at Least Once	*75	*65	*67	*71	*62
Formal Diagnosis Indicating the Presence of a Special Need	**13	**12	**8	**13	**10
<b>Identified as CSHCN</b>					
QuICCC	*35	*23	*33	*34	*27
QuICCC-R	*34	*21	*33	*34	*28
CSHCN Screener	*28	*17	*18	*26	*19

\* Significant  $p < 0.001$ .

\*\*Not significant.

NOTES: CSHCN is children with special health care needs. QuICCC is Questionnaire for Identifying Children with Chronic Conditions. QuICCC-R is a shorter, revised version of QuICCC.

SOURCE: (Stein, Westbrook, and Bauman, 1997.)

Hispanic children ( $\chi^2 = 5.87, p < 0.01541$ ). A similar pattern was observed for the QuICCC-R ( $\chi^2 = 5.14, p = 0.0234$ ) and the CSHCN Screener ( $\chi^2 = 8.37, p = 0.0038$ ).

## Regression Results

### Health Care Use and System Special Needs Diagnoses

Both health and sociodemographic variables were related to the odds of a child using health care services at least once (Table 3). Children in fair to poor health had odds that were two times greater than children in excellent health of using the health care system. Greater odds of use also were seen for children in good or very good health when compared with those in excellent health.

After controlling for certain other variables in the model, children who were black had significantly lower odds (0.69) of using the health care system than white children (1.00). The odds of multiracial children using the health care system at

least once were not significantly different from those of white children. Hispanic children had odds of use that were 0.85 that of non-Hispanic children (1.00). Age, sex, respondent education, and family income were not significantly related to the odds of children using health care services. However, the number of months the child was enrolled in the program was significant, with longer enrollment associated with higher odds of use.

Only children who used the health care system at least once were included in the logistic regression examining the odds of having a formal special needs diagnosis. The odds of those in fair to poor health having a diagnosis indicative of a special health care need were 3.87 times that of children in excellent health (1.00). Children in good to very good health also had significantly higher odds of having a formal diagnosis indicating a special health care need when compared with children in excellent health (2.12 and 1.46, respectively). No significant differences were noted in the odds of black, multiracial, or Hispanic

**Table 3**  
**Logistic Regression Models: Odds Ratio of Using Health Care Services<sup>1</sup> and Having a Special Health Care Need, Given Use**

Variable	Using Health Care Services			Having a Formal Special Needs Diagnosis, Given Health Care Use		
	Odds Ratio	95 Percent CI	P	Odds Ratio	95 Percent CI	P
<b>Health Status</b>						
Fair to Poor	2.10	1.39, 3.26	0.0006	3.87	2.61, 5.73	<0.0001
Good	1.61	1.30, 2.02	<0.0001	2.12	1.68, 2.69	<0.0001
Very Good	1.25	1.04, 1.51	0.0185	1.46	1.17, 1.82	0.0007
Excellent	1.00	NA	NA	1.00	NA	NA
<b>Race</b>						
Black	0.69	0.51, 0.91	0.009	1.031	0.68, 1.57	0.8867
Other	0.82	0.59, 1.14	0.2347	0.67	0.38, 1.17	0.1612
White	1.00	NA	NA	1.00	NA	NA
<b>Ethnicity</b>						
Hispanic	0.85	0.64, 1.13	0.2654	0.69	0.44, 1.10	0.1228
Non-Hispanic	1.00	NA	NA	1.00	NA	NA
<b>Age</b>						
6-11 Years	0.81	0.51, 1.28	0.3719	1.45	0.68, 3.09	0.33366
12-19 Years	0.91	0.57, 1.46	0.7057	1.54	0.72, 3.29	0.2696
5 Years and Under	1.00	NA	NA	1.00	NA	NA
<b>Sex</b>						
Male	0.82	0.66, 1.02	0.0839	1.75	1.27, 2.41	0.0006
Female	1.00	NA	NA	1.00	NA	NA
<b>Respondent Education</b>						
High School Graduate	0.98	0.67, 1.43	0.9072	1.11	0.63, 1.95	0.7255
Technical/Trade School	1.05	0.72, 1.54	0.8039	1.12	0.64, 1.99	0.6797
College Graduate and Higher	1.37	0.88, 2.12	0.1665	0.92	0.48, 1.77	0.7972
Less than High School	1.00	NA	NA	1.00	NA	NA
<b>Family Income</b>						
Below 133 Percent FPL	0.88	0.52, 1.49	0.6377	1.55	0.70, 3.42	0.2785
133 to 150 Percent FPL	1.49	0.77, 2.89	0.236	1.66	0.66, 4.14	0.28
150 to 200 Percent FPL	1.26	0.71, 2.24	0.4316	1.47	0.63, 3.41	0.3707
200 Percent FPL or Above	1.00	NA	NA	1.00	NA	NA
<b>Months Enrolled</b>						
6 Months or More	1.23	1.19, 1.26	<0.0001	0.88	0.84, 0.92	<0.0001
Less than 6 Months	1.00	NA	NA	1.00	NA	NA

<sup>1</sup> Only children who used the health care system at least once were included in the model.

NOTES: CI is confidence interval. FPL is Federal poverty level. NA is not applicable.

SOURCE: (Stein, Westbrook, and Bauman, 1997.)

children having special needs diagnoses when compared with white or non-Hispanic children. The child's age, respondent education, and family income, also were not significantly related to the odds of a child having a special needs diagnosis. Males had greater odds of being diagnosed

with special health care needs than females. Children enrolled in the program for 6 months or more had significantly lower odds of having formal diagnoses indicating special health care needs (0.84) when compared with children enrolled for less than 6 months.

## Identification of Special Needs Children

Parent's perceptions of their children's health status were significantly related to the odds of the child being identified as having a special health care need using each of the screening instruments (Table 4). For example, children who were reported to be in fair to poor health were 15.8 times more likely to be identified as having a special health care need using the QuICCC when compared with children in excellent health (1.00). Children who were identified as having a special health care need based on ICD-9-CM codes were 3.8 times more likely than children without such diagnoses to be identified as having a special need using the QuICCC. The same pattern was seen for the QuICCC-R and the CSHCN Screener where children in poorer health and those with ICD-9-CM codes indicating a special need had significantly higher odds of being identified with special health care needs using those screening instruments than children without those characteristics.

Some demographic variables were significantly related to whether the child was identified as having a special health care need using the screening instruments. For example, the odds of a black child being identified with a special health care need using the QuICCC was 0.41 times that of a white child (1.00). The same pattern was seen for the QuICCC-R and the CSHCN Screener. For the QuICCC and the QuICCC-R, there were no significant differences between multiracial and white children in the identification of those with special health care needs. However, using the CSHCN Screener, multiracial children were 0.62 times as likely as white children (1.00) to be identified with a special health care need. Children who were Hispanic also had significantly lower odds of being identified with special health care needs

using any of the screening instruments when compared with non-Hispanic children. The odds of identifying a Hispanic child with a special health care need was 64 percent that of a white child using the QuICCC, 66 percent using the QuICCC-R, and 63 percent using the CSHCN screener.

The child's age, family income, and months enrolled were not significantly related to the odds of the child being identified as having a special health care need using any of the screeners. Using the QuICCC-R, males had significantly higher odds than females of being identified with special health care needs (1.33). However, sex was not significant for the QuICCC or the CSHCN Screener. Respondents with some vocational or educational training had significantly higher odds of having children identified with special health care needs using the QuICCC-R (1.57) or the CSHCN Screener (2.03) when compared with respondents with less than a high school education (1.00).

## DISCUSSION

The development of survey screening tools to identify children with special health care needs is a positive step forward in improving their access to quality health care. Once identified, these children can be referred for needed health care services and monitored closely for variations in the quality of their care (Newacheck et al., 2000). In addition, information about the numbers of these children can be used to better plan programs and services to meet their needs.

CSHCN who also are members of racial and ethnic minority groups are particularly important to identify. Parents of children who are Hispanic or black are more likely to report that their children are in fair to poor health when compared with parents of white children (Newacheck et al., 1998;

Table 4

### Logistic Regression Analyses: Relationship Between Child Health and Socioeconomic Variables and Identification of Special Health Care Needs

Variable	QuiCCC			QuiCCC-R			CSHCN Screener		
	Odds Ratio	95 percent CI	P	Odds Ratio	95 Percent CI	P	Odds Ratio	95 Percent CI	P
<b>Health Status</b>									
Poor to Fair	15.79	8.40, 29.67	<0.0001	19.07	10.22, 35.57	<0.0001	23.18	12.82, 41.96	<0.0001
Good	3.35	2.51, 4.48	<0.0001	3.93	2.92, 5.28	<0.0001	3.38	2.43, 4.70	<0.0001
Very Good	1.74	1.36, 2.24	<0.0001	2.07	1.60, 2.68	<0.0001	2.15	1.60, 2.89	<0.0001
Excellent	1.00	NA	NA	1.00	NA	NA	1.00	NA	NA
<b>Special Health Care Need<sup>1</sup></b>									
Yes	3.79	2.72, 5.30	<0.0001	3.71	2.68, 5.14	<0.0001	4.22	3.04, 5.87	<0.0001
No	1.00	NA	NA	1.00	NA	NA	1.00	NA	NA
<b>Race</b>									
Black	0.41	0.30, 0.56	<0.0001	0.4	0.29, 0.55	<0.0001	0.32	0.22, 0.47	<0.0001
Other	0.9	0.64, 1.24	0.4873	0.89	0.63, 1.25	0.5034	0.62	0.41, 0.92	0.018
White	1.00	NA	NA	1.00	NA	NA	1.00	NA	NA
<b>Ethnicity</b>									
Hispanic	0.65	0.49, 0.87	<0.0033	0.66	0.49, 0.89	0.0067	0.64	0.46, 0.90	<0.0109
Non-Hispanic	1.00	NA	NA	1.00	NA	NA	1.00	NA	NA
<b>Age</b>									
6-11 Years	1.17	0.85, 2.73	0.1895	1.51	0.90, 2.53	0.1182	1.33	0.73, 2.42	0.3467
12-19 Years	1.38	0.84, 2.26	0.2085	1.44	0.86, 2.43	0.1682	1.38	0.76, 2.52	0.2911
5 Years and Under	1.00	NA	NA	1.00	NA	NA	1.00	NA	NA
<b>Sex</b>									
Male	1.17	0.94, 1.43	0.1628	1.33	1.05, 1.63	0.0155	1.22	0.95, 1.56	0.1168
Female	1.00	NA	NA	1.00	NA	NA	1.00	NA	NA
<b>Respondent Education</b>									
High School Graduate	0.85	0.56, 1.23	0.3935	1.04	0.74, 1.54	0.8433	1.22	0.76, 1.91	0.4205
Technical/Trade School	1.3	0.89, 1.90	0.1597	1.57	1.06, 2.33	0.0243	2.03	1.28, 3.20	0.0025
College Graduate or Higher	1.00	0.65, 1.54	0.9954	1.24	0.79, 1.94	0.3465	1.48	0.88, 2.50	0.1422
Less than High School	1.00	NA	NA	1.00	NA	NA	1.00	NA	NA

See footnotes at end of table.

**Table 4—Continued**  
**Logistic Regression Analyses: Relationship Between Child Health and Socioeconomic Variables and Identification of Special Health Care Needs**

Variable	QuICCC		P	QuICCC-R		P	CSHCN Screener		
	Odds Ratio	95 percent CI		Odds Ratio	95 Percent CI		Odds Ratio	95 Percent CI	P
<b>Family Income</b>									
Below 133 Percent FPL	1.21	0.73, 2.00	0.4685	1.1	0.66, 1.85	0.7194	1.08	0.61, 1.92	0.7818
133 to 150 Percent FPL	1.22	0.67, 2.38	0.5202	1.18	0.64, 2.21	0.5993	0.92	0.45, 1.84	0.8018
150 to 200 Percent FPL	1.54	0.90, 2.65	0.1189	1.34	0.77, 2.33	0.2993	1.11	0.60, 2.06	0.7301
200 Percent or Above FPL	1.00	NA	NA	1.00	NA	NA	1.00	NA	NA
<b>Months Enrolled</b>									
More than 6 months	1.02	0.80, 1.23	0.9203	1.00	0.79, 1.27	0.9847	0.99	0.76, 1.30	0.9764
Less than 6 Months	1.00	NA	NA	1.00	NA	NA	1.00	NA	NA

<sup>1</sup> Based on *International Classification of Diseases, 9th Revision, Clinical Modification* codes.

NOTES: QuICCC is Questionnaire for Identifying Children with Chronic Conditions. QuICCC-R is a shorter, revised version of QuICCC. CSHCN is children with special health care needs. CI is confidence interval. FPL is Federal poverty level. NA is not applicable.

SOURCE: (Stein, Westbrook, and Bauman, 1997.)

Arcia, 1998). Given their poor reported health status, these children could benefit from early identification of special health care needs and prompt referrals. However, little information is available about how instruments such as the QuICCC, the QuICCC-R, and the CSHCN Screener perform when given to parents who are black or Hispanic. The focus of our study was to examine the influence of health-related, race, and ethnicity variables on the odds that a child would be identified as having a special health care need using the QuICCC, the QuICCC-R, and the CSHCN Screener.

In two major respects each of the three screening instruments used in this study performed as expected. Children with formal diagnoses indicative of special health care needs and those in fair to poor health had significantly greater odds of being identified with special needs using the screening instruments than those without formal diagnoses and those in good to excellent health.

However, both race and ethnicity were associated with significantly lower odds of the child being identified with a special health care need using the QuICCC, the QuICCC-R, and the CSHCN Screener. These findings were unexpected. Several studies have demonstrated that minority status, income, and education are associated with poorer health and chronic conditions (Sorlie, Backlund, and Keller, 1995; Starfield and Budetti, 1985). In a study using National Health Interview Survey data, black children were most likely to be identified with chronic conditions and Hispanic children least likely (Newacheck et al., 1998). Yet in our study, the screening instruments identified fewer black and Hispanic children relative to white and non-Hispanic children, respectively. Our study finding related to black children is different than what one might expect,

while the finding related to Hispanic children is expected, based on the National Health Interview Survey data.

Our findings raise questions about the performance of the screening instruments in identifying those with special health care needs among black or Hispanic children. In our study, respondents who were black were significantly more likely to rate their children in good to poor health and less likely to report very good to excellent health when compared with white respondents. Similarly, a higher percentage of Hispanic families rated their children in good to poor health as opposed to very good to excellent health when compared with non-Hispanic families. Despite perceived poorer health status, black and Hispanic children were significantly less likely than white or non-Hispanic children respectively to be identified with special health care needs based on the screening instruments.

Moreover, in our study, we determined that once children used the health care system at least once, there were no differences in the odds of black or Hispanic children having a formal special health care needs diagnosis compared with white or non-Hispanic children, respectively. There also were no significant differences noted in the odds of multiracial children having a formal special health care needs diagnosis when compared with white children. Thus, we would not expect differences in the identification of children with special health care needs using the screening instruments based on race and ethnicity.

Our study findings raise two primary questions about the performance of these screening instruments. First, are the screening instruments measuring access to health care in addition to the presence of special health care needs? Second, are there racial and ethnic differences in expectations of or perceived need for

health care that may contribute to the under identification of black and Hispanic children with special health care needs relative to white and non-Hispanic children respectively using these instruments?

The screening tools focus heavily on actual health care use or the perceived need for health care use. For example, each screening tool asks about the need for or actual (1) elevated health care service use, (2) medication use, or (3) mental health services use. An affirmative answer to any of the use categories coupled with the presence or expected presence of a condition for 12 months or longer, identifies the child as having a special health care need. Answering these questions in the affirmative implies that the respondent understands the questions, has knowledge of the child's health care needs, and that the child has access to the health care system.

The smaller odds of identification for black and Hispanic children relative to white and non-Hispanic children respectively may reflect limited access to care as opposed to a lower incidence of special needs among black and Hispanic pediatric populations. In fact, our analyses demonstrate that black children in our study have less access to care than white children or multiracial children, as demonstrated by their significantly lower odds of using the health care system at least once during the study period. Black families may simply not have sufficient access to the health care system and therefore their children do not have elevated physical or mental health care service use or medication use. Given that elevated health care service and medication use are two important areas of questioning on the screening instruments, children without access to these services may not be detected as having special health care needs using these instruments.

Diminished access to care may also affect perceived need for health care. For example, in a study of Hispanic families' responses to questions about unmet health care needs, investigators noted that the perception of need is based, in part, on experience with the health care system (Health Care Financing and Organization Issue Brief, 2001). If an individual does not use the health care system, he or she may not realize that certain health care needs exist. Perceived need is an important component of the questions on each of the three screening instruments used in our study. To the extent that families face restricted access to care, they may not have enough health care knowledge or experience to know that their children need medications or increased health care services.

The odds of Hispanic children using health care services were not significantly different from those of non-Hispanic children. Hispanic children were perceived to be in poorer health by their parents when compared with non-Hispanic children. In addition, they had similar odds of having a formal diagnosis indicating a special health care need as non-Hispanic children. Yet Hispanic children had odds of being identified as having a special health care need using one of the screening instruments that were 0.66 to 0.64 times those of white children (Table 4).

This finding raises the possibility that important differences may exist between Hispanic respondents' interpretation of and their response to screening questions about their children's health. For example, some people among Hispanic populations rely on a mixture of folk medicine and conventional care to meet their health care needs (Krajewski-Jaime, 1999). To the extent that families rely on folk medicine,

the questions on the screening instruments, which focus heavily on the use of medications and professional medical services, may not reflect their experiences in obtaining health care for their children.

This study has two primary limitations. First, the study was conducted with a group of Title XXI enrollees in Florida. It is possible that our findings are not generalizable beyond this group. We do not have any reason to believe that the children in Florida's Title XXI Program differ from those in other States' Title XXI programs. However, these children are in low-income families, between 100 and 200 percent of the Federal poverty level. It is possible that their parents' interpret the questions on the screening instruments differently or have different health care experiences than higher income families or very poor families (below 100 percent FPL).

Second, at the time this study was conducted, CSHCN severe enough to meet the medical eligibility criteria for the State Title V CSHCN Program, were not enrolled in the Healthy Kids Program. The Title V medical eligibility criteria are stringent and children with mild to moderate special health care needs such as asthma, diabetes, and a wide range of mental health conditions do not qualify for the program. These children remain in the Healthy Kids Program along with children who have a variety of conditions including cardiovascular, orthopedic, and central nervous system disorders that are not of sufficient severity to enter the Title V Program. In prior analyses, approximately 1 percent of the children in Title XXI have special health care needs severe enough to meet the Title V Program medical eligibility criteria (Shenkman and Col, 2001). It is possible that different results would be obtained if a Title V Program population were included in the analyses.

In summary, each screening instrument was carefully developed and tested. Children with poor reported health status, and those with ICD-9-CM codes indicating a special health care need were more likely to be identified as having a special health care need by the screening instruments than children without those circumstances. However, children who are black or Hispanic are less likely to be identified after controlling for health status variables and other sociodemographic predictors.

Our research suggests that, while the instruments perform well on many dimensions, further study with children who are black or Hispanic may be warranted. In addition, other options to identify children with special health care needs who are black or Hispanic may need to be explored. Perhaps these children need to be identified through personal interviews, as opposed to written or telephone survey screening. Further research is needed to refine approaches for identifying children with special needs from a variety of racial and ethnic backgrounds.

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