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# DENTAL CARE AND CHILDREN WITH SPECIAL HEALTH CARE NEEDS: A POPULATION-BASED PERSPECTIVE

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#### **Abstract**

This paper grew out of a project reviewing progress in children's oral health since the Surgeon General's Report (SGR) on Oral Health. It includes a summary of advances in national surveillance of children with special health care needs (CSHCN), and presents more recent data on unmet dental care need among CSHCN. To that end, we used the 2006-National Survey of CSHCN to determine the prevalence of unmet dental care need among CSHCN and to compare this within subgroups of CSHCN, as well as to children without special health care needs, and to results from the previous iteration of this survey.

We found that dental care remains the most frequently cited unmet health need for CSHCN. More CSHCN had unmet need for non-preventive than preventive dental care. CSHCN who are teens, poorer, uninsured, had insurance lapses, or more severely affected by their condition had higher adjusted odds of unmet dental care needs. CSHCN who were both low-income and severely affected had 13.4 times the adjusted odds of unmet dental care need.

In summary, CSHCN are more likely to be insured and to receive preventive dental care at equal or higher rates than children without SHCN. Nevertheless, CSHCN, particularly lower income and severely affected, are more likely to report unmet dental care need compared to unaffected children. Despite advances in knowledge about dental care among CSHCN, unanswered questions remain. We provide recommendations towards obtaining additional data and facilitating dental care access for this vulnerable population.

#### **Keywords**

Dental Care; Children; Special Health Care Needs; Oral health; Disability

# INTRODUCTION

This paper grew out of an American Academy of Pediatrics project reviewing progress in the area of children's oral health since the Surgeon General's Report on Oral Health. It includes a summary of key advances in national dental care and oral health surveillance of children with special health care needs (CSHCN), and presents more recent national data on dental care need

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among CSHCN. Prior to the year 2000, there existed no population-based study describing the dental care utilization or needs among children with special health care needs (CSHCN) residing in the United States. When Oral Health in America: a Report of the Surgeon General was published that year, <sup>1</sup> it addressed oral health of disabled populations only briefly, in large part, according to the authors, because there were such limited data available. In April, 2000, Newacheck and colleagues published a sentinel paper entitled, Access to Health Care for Children with Special Health Care Needs. <sup>2</sup> This paper relied on data from the 1994-5 National Health Interview Survey (NHIS) on Disability and represents the first time, to our knowledge, that dental care was described as the leading unmet health care need among US CSHCN.

Since Newacheck's article, other population-based studies have been published, furthering our understanding of dental care needs and access of CSHCN. Key to expansion of research on this topic was the formal definition of CSHCN by the Maternal and Child Health Bureau (MCHB) (textbox)<sup>3</sup> as well as the development of a screening instrument that operationalized this definition. This validated tool, called The Children with Special Health Care Needs Screener, 3 is intended to be broadly inclusive and non-condition specific and dichotomously classifies children as having a special health care need (SHCN) or not. The CSHCN screener is now a component of several national surveys including the Medical Expenditure Panel Survey (MEPS) administered by the US Agency for Health Care Quality and Research (AHRQ),<sup>4</sup> the National Survey of Children with Special Health Care Needs (NS-CSHCN),<sup>5</sup> and the National Survey of Children's Health (NSCH). <sup>6</sup> The latter 2 are MCHB-funded surveys conducted by the National Center for Health Statistics (NCHS) of the CDC (Centers for Disease Control). The capability to uniformly define CSHCN and relate this to the dental care and oral health variables within these 3 nationally-representative surveys has produced a respectable expansion in oral health research focused on US CSHCN in the last decade. We summarized published dental -related findings from these surveys in Table 1.

The second iteration of the NS-CSHCN ("2006 NS-CSHCN")<sup>5</sup> is the focus of this research. Some revisions since the 2001 NS-CSHCN were relevant to better understanding dental care needs of CSHCN. Specifically, in the 2006 version, we are now better able to identify specific subgroups with more unmet dental care need, to separate out preventive vs. "other dental care" (e.g. fillings and other restorative dental care) and to make comparisons between children with and without SHCN. Without a non-special needs comparator group, it had previously been difficult to know whether disparities in dental care access were associated with a child's special need or with other factors that may disproportionately affect CSHCN.

We had the following objectives: 1) to determine, from a population perspective, a more current prevalence of unmet dental care needs, including preventive and other dental care, among CSHCN and compare this to children without SHCN, 2) within the constraints of cross-sectional data, to compare 2001 CSHCN findings to those of 5 years later, and 3) to identify factors associated with a greater odds of unmet dental care needs in CSHCN. We were particularly interested in the impact of condition severity as well as whether poverty, which we knew from our previous work to be an independent risk factor for unmet dental care, mediated the effect of condition severity on unmet dental care need.

#### **METHODS**

This version of the NS-CSHCN was administered between April 2005 and February 2007. The State and Local Area Integrated Telephone Survey (SLAITS),<sup>7</sup> a mechanism developed by the NCHS to collect state and nationally-representative data via random digit dialing, was employed to identify and interview parents of 750 CSHCN from each of 50 states and the District of Columbia. Children were determined to have a special health care need based on their parent/caregivers' responses to the CSHCN screener. The questionnaire was also

administered to a nationally representative referent sample of caregivers of children without SHCN so that comparisons could be made between children with and without SHCN. Data are publicly available from the NCHS/SLAITS website.<sup>7</sup>

### **Study Design**

We merged the 3 data files that comprised the NS-CSHCN, i.e., screener, household, and interview. Our outcome variables of interest were unmet need for 1) preventive dental care, 2) other dental care, and 3) any dental care. There were 2 survey items about dental care need: whether the child needed <u>preventive</u> dental care and whether he/she needed <u>other</u> dental care in the previous 12 months (or since birth for children under 12 months of age). Following an affirmative response to either of these questions, another item addressed whether the child received all of that type of dental care that he/she needed. Children who needed either preventive or other dental care but did not receive all of that type of care were classified as having an unmet preventive or other dental care need, respectively. Having either or both preventive/other dental care unmet need meant a child had an unmet need for "any dental care". We compared unmet need for the 3 categories of dental care (preventive, other, any) between children with and without SHCN. Additionally, we determined the number of CSHCN with unmet need for other health care categories (e.g., mental health services) for comparison with unmet dental care need. We also assessed the prevalence of unmet dental care need among CSHCN with select diagnoses (e.g., asthma, autism, Down syndrome).

Covariates examined in multivariable logistic regression analyses for their relationship to unmet dental care need were chosen on the basis of *a priori* hypotheses and categorized into the following 3 groups: (1) Sociodemographic characteristics, which included: child's race/ethnicity and family income relative to the Federal Poverty Level (FPL); (2) Health Care, which included: current health insurance type, lapsed insurance in the year (from the item: "During the past 12 months was there any time when your child was not covered by any health insurance?"), and having a personal doctor or nurse (defined as "a health professional who knows your child well and is familiar with your child's health history"), and (3) Condition Severity.

We developed age, race/ethnicity, and insurance status categories from the range of options available in the original data. We collapsed race and ethnicity into a single variable to give 5 racial/ethnic categories-white, Latino, black, multiracial and other. Age was categorized into 3 groups—under 6, 6-12, and 13-17 years. As in the 2001 NS-CSHCN, there was no question in the survey about dental insurance, and thus we used current medical insurance status as a proxy. Three medical insurance categories were defined--private, public, or uninsured. Condition severity was established based on parents' responses to 2 questions—1) how often the child was affected by his/her condition and 2) the degree that the child's condition affected his/her abilities. Children whose parents said their condition never affected them were placed in the "no impact" category, which was the lowest severity group. Only children who were said to have conditions that affected them in some way were asked, "Does your child's (medical, behavioral, or other health conditions/emotional, developmental, or behavioral problems) affect (his/her) ability to do things a great deal, some, or very little?"8 Responses to this question were used to categorize children into the 3 other severity categories so that, in the end, there were 4 categories of condition severity; no impact, very little impact, some impact or a great deal of impact on the child's abilities.

# **Analyses**

Data were analyzed with Stata software, version 10.0 (Stata Corp, College Station, TX). We used Stata survey commands and the population weights provided in the data files to account for the complex sampling design and to generate population level estimates. We conducted

multivariable logistic regression analysis on the outcome of unmet need for any dental care. To address our specific interest in the impact of poverty on severely affected CSHCN, we conducted a second multivariable logistic regression model, also on the outcome of unmet need for any dental care, which included an interaction term combining income relative to FPL and condition severity. For ease of this analysis, we collapsed income categories into 3 groups: below 200% FPL, 200-399% FPL and 400% FPL and higher. We retained the original 4 categories of condition severity. The lincom procedure in Stata was used to generate adjusted odds ratios (AOR) and 95% confidence intervals (95% CI) from the model containing the interaction term.

## **RESULTS**

There were 40,840 completed interviews for CSHCN and 6,113 completed interviews for children in the referent sample (i.e., children without SHCN), representing 8.8 million CSHCN and 61 million children without SHCN, respectively. Characteristics of CSHCN are presented in Table 2. Overall, 81% of CSHCN were reported as needing preventive dental care and 24% as needing other dental care in the past 12 months. Dental care was second only to prescription medications in the frequency of need. Of those who reported needing preventive or other dental care, there was unmet dental need among 7.4% for preventive dental care and 10.3% for other dental care. Overall, 579,477 children, or 8.9% of CSHCN who needed any dental care were unable to obtain it (Table 2). Relative to all other health care service categories, unmet dental care needs was the most common unmet need for CSHCN. Mental health was the next most prevalent unmet health care need, impacting 278,244 CSHCN or about half as many children as had unmet dental care needs. The third most often cited unmet need was for physical, occupational or speech therapy, which affected 235,455 CSHCN.

When parents were asked why a CSHCN did not receive needed preventive dental care, the leading reasons were similar to those reported by parents of children without SHCN: too costly was most the common reason (of those with unmet dental care need: 25% of CSHCN vs. 38% of children without SHCN), followed by lack of insurance (of those with unmet dental care need: 22% of CSHCN vs. 30% of children without SHCN). Almost no respondents (unweighted N=11) listed the need for a special health care needs dentist as the reason for not being able to obtain needed preventive dental care.

A significantly higher proportion of CSHCN relative to children without SHCN had unmet dental care needs (p<0.0001) (Figure 1). We also found differences in unmet dental need by condition severity; 20% of severely affected CSHCN had unmet other dental care needs compared to 5% of CSHCN whose condition did not impact them at all. The difference for unmet preventive dental care between the 2 extremes of condition severity was only slightly less striking (4 vs. 15%). In fact, CSHCN who are not impacted by their condition at all were similar to their non-special need counterparts in unmet need for any dental care, affecting ~5% of each group. The proportion of children with unmet dental care needs also varied by specific condition. Children with Down syndrome had the highest proportion of unmet dental care needs at 17.4% and children with asthma the lowest at 8.6% (Figure 2).

In examining the association between unmet dental care needs and various potential explanatory variables using multivariable regression analysis (Table 2), we found that CSHCN who were adolescents (relative to under 6 year olds), had family incomes less than 400% FPL, were uninsured, had lapsed insurance, or were more severely affected had significantly higher adjusted odds of unmet dental care need. There was a statistically significant trend for higher odds of unmet dental care need with increasing levels of poverty (p<0.0001) and by worsening condition severity (from no impact to a great deal of impact, p<0.0001). Results of the logistic model with the interaction term combining income relative to FPL category and condition

severity demonstrated AOR of unmet dental need among severely affected children that ranged from greater than 13 in the poor/low-income children to almost 4 in the highest income group (Figure 3).

# **DISCUSSION**

In this study of the 2005 NS-CSHCN, about 9% of CSHCN who needed dental care were unable to obtain it compared to 5% of children without special needs. Although dental care remains the leading unmet health care need for CSHCN, 23% fewer CSHCN had unmet dental care needs compared to the 2001 survey (755,581 in 2001 vs. 579,477 in 2005), even though more CSHCN were said to have needed preventive dental care in 2005-2006 (78% in 2001 vs. 81% in 2005-2006). Nevertheless, there remains considerable disparity in ability to obtain needed care by degree of poverty and condition severity. With 13.4 times the adjusted odds of unmet dental care need for severely affected, poor/low-income CSHCN relative to unaffected high-income children, we are far from our goal of ensuring that all children are able to obtain the dental care that they need. These results emphasize the importance of attending to the dental care needs of our nation's most vulnerable children. Similar to our studies in all US children, having public insurance such as Medicaid or SCHIP, and race/ethnicity were not, in general, significantly associated with unmet dental care needs in CSHCN after adjusting for family income relative to FPL. 10,11

Separate questions about preventive and other dental care made it possible to characterize unmet need for specific category of dental care, something not previously reported. We found that there is more unmet need for <u>other</u> dental care than for <u>preventive</u> dental care among CSHCN. Delivering preventive dental care to a CSHCN is very important, however it tends to be more straight forward than restorative care, which can be time-consuming and laborintensive for dental professionals, particularly if the child is more severely affected. Restorative dental care is also more expensive and more of the cost burden for such care is borne by families of CSHCN, which may help to explain why other dental care needs were less often met.

We identified that CSHCN with certain diagnoses including Down syndrome, other forms of mental retardation, cerebral palsy and autism encounter greater difficulty obtaining needed dental care, although what it is specifically about these diagnoses that interfere with dental care receipt remains unclear. It may be that these diagnoses merely represent more severely affected children. There were significant differences in the proportion of CSHCN with unmet dental care need as condition severity worsened. Moreover, the association between condition severity and unmet dental care needs was mediated by income. To our knowledge, this is the first time that a child's condition severity, whether considered alone or as a function of their income, have been independently related to unmet dental care need. Although poor/low-income, severely affected CSHCN had a high adjusted odds ratio of unmet dental care need, even having a family income at/above 400% FPL was not fully protective against unmet dental care needs for those most severely affected. These children may be so compromised by their underlying condition that they require specialized services, which may not be readily available, <sup>12</sup> in order receive to dental care. Yet, almost no parent cited lack of availability of dentists specifically trained in the care of CSHCN as an obstacle to their child's receipt of dental care. It may be availability of hospital-based dental services, 12 which are more likely to be required for severely affected children, as opposed to specifically trained dentists, that poses the greatest barrier to obtaining needed dental care in these parents' eyes. Additional research is needed to clarify the exact nature of barriers for severely affected CSHCN.

There are certain limitations to this research and other studies from this and similar surveys. Responses to survey questions are based on a parental report and are thus subject to bias. Additionally, of the many topics and questions considered for inclusion in national surveys,

only a limited number are possible and most are broadly focused, leaving unanswered questions. We still know very little about the specific factors that interfere with severely affected CSHCN obtaining dental care. Nevertheless, findings from these surveys provide the basis for research questions better answered in smaller scale studies. There are however, some omissions to the NS-CSHCN that pose particular obstacles to studying dental care need among CSHCN and that deserve remedy—specifically, the lack of any items related to dental insurance. We were forced to rely on medical insurance as a proxy for dental coverage. But since 2.5 times as many children are uninsured for dental relative to medical care, <sup>10</sup> this is suboptimal substitute. Finally, differences in unmet dental care need by condition severity demonstrate the shortcoming of considering all CSHCN as a single group, as occurs when the CSHCN Screener is used to dichotomously classify children at having a SHCN or not.. As we have seen, such an approach does not allow for an adequate picture of the dental needs of certain subgroups. By including children with little or no impairment among CSHCN, we are diluting out the difficulty experienced by more severely affected children when they try to obtain dental care.

#### CONCLUSIONS AND RECOMMENDATIONS

In this paper, we sought to describe what we have learned about dental care for US CSHCN since release of the Surgeon General's report in the year 2000. Indeed, almost everything known about this subject, we have learned from studies in the last decade. Results are remarkably consistent between studies in describing relatively equal rates of preventive dental care use by children with and without SHCN. 13-15 However, researchers have also reported more unmet dental care need<sup>2, 9, 13, 14</sup> and worse oral health among CSHCN relative to their non-SHCN peers. <sup>14</sup>, <sup>16</sup> Findings from the 2006 NS-CSHCN confirm the anecdotal impression that there is more unmet need for other dental care than for preventive dental care and that condition severity is significantly associated with unmet dental care need. Furthermore, we found that poor and low-income children with more severe conditions have more than 13 times the adjusted odds for unmet dental care needs compared to high-income unaffected children. Children facing the "double disparity" of poverty and a severe chronic condition deserve special attention from clinicians and policy makers to alleviate such marked difficulty obtaining needed dental care. Regardless of income, at least 90% of severely affected CSHCN had a personal doctor or nurse, which reinforces the importance of including dental care as part of the comprehensive care coordinated by the medical home. <sup>9,17</sup>

Despite advances in our understanding of dental care utilization and needs among CSHCN, a number of unanswered questions remain. Specifically, it remains unclear exactly what factors interfere with certain CSHCN obtaining needed dental care. It is possible that a system of specialized referral centers, adequately staffed to provide timely preventive and restorative dental care to severely affected CSHCN within a given region, may help to better address dental care need for these children. In such a model, general and pediatric dentists would continue to care for mildly and moderately affected CSHCN in or near their home communities. To our knowledge, no one has proposed such a system. However, the degree of disparity in unmet dental care needs for severely affected children identified in this study should provide the basis for additional research directed at better understanding modifiable barriers to dental care for these children.

Designing a system of care specifically for more severely affected CSHCN also would require objective data about the actual dental health of CSHCN, such as would be obtained from oral examination. Although there exists a mechanism, in the form of the ongoing National Health and Nutrition Examination Survey (NHANES), to measure national prevalence of oral disease, the accompanying NHANES questionnaire includes only a very limited number of items that could identify a child as having a special need (e.g., special education use). <sup>18</sup> We recommend

inclusion of the CSHCN screener and condition severity items in the NHANES questionnaire as well as an oversampling (to improve precision in the resulting nationally representative estimates) of severely affected CSHCN who receive dental examinations as a part of NHANES.

Revisions to national survey instruments could further enhance our understanding of dental care need among CSHCN. The NS-CSHCN includes questions related to assessing satisfaction with health care, improving quality of care and communication between medical providers and families, and better understanding the impact of health problems on the family. However, there are no such parallel questions about satisfaction with or quality of dental care, about content or quality of communication between family and dentist, or how dental problems impact the child and their family. That dental topics are underrepresented only serves to reinforce that dental care is not yet fully integrated into overall health care. We urge an expansion in dental-related questions in these surveys.

The last 10 years have brought considerable gains in our knowledge about dental care need and use among US CSHCN. These would not have been possible without efforts on the part of the MCHB,AHRQ, CDC, and NCHS to develop and implement nationally representative surveys focused on or specifically inclusive of CSHCN. A number of questions about dental care for CSHCN remain but we are now closer to our goal of better understanding the dental care needs of CSHCN and of developing systems of care to meet these needs.

"Children who have special health care needs are those who have (or who are at 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"

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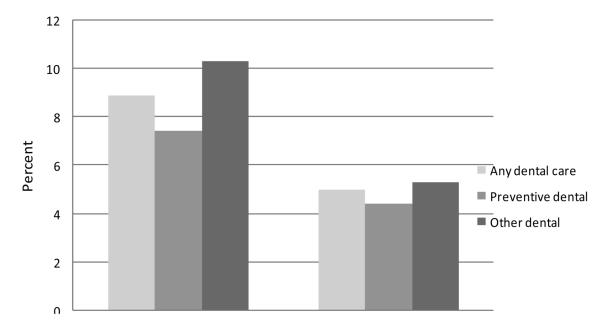
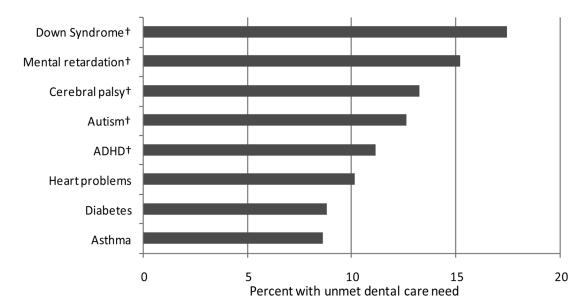


Figure 1.

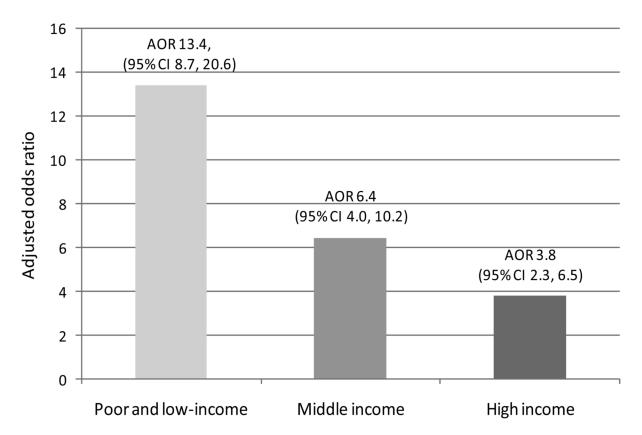
Percent of children needing dental care, with and without SHCN, who had unmet dental care need, by type of dental care\*\*\*

\*\*\*p<.0001 for each comparison between children with and without SHCN for each type of



†Significantly different from other CSHCN, p<.0001

**Figure 2.** Percent CSHCN with unmet dental care need by diagnosis



**Figure 3.**Adjusted odds ratios (AOR) of unmet dental care needs by income category among severely affected CSHCNT
T Reference category is high-income CSHCN whose condition does not impact them at all

Table 1

Summary of published studies from nationally representative survey including CSHCN with dental-related findings

TINGINGS STUDY AND YEAR DATA AND STUDY OBJECTIVE DENTAL-RELATED FINDINGS					
	YEAR COLLECTED				
Newacheck et al, 2000 <sup>2</sup>	Disability, 1995		The most prevalent unmet needs was for dental care (8.1% of CSHCN) vs. 3.2% unmet need for medical care. Among uninsured CSHCN 24% had unmet dental care needs compared to 6% of insured CSHCN.		
Newacheck and Kim, 2005 <sup>15</sup>			CSHCN and children without SHCN had similar numbers of annual dental care visits (1.2-1.3 visits/year). Out-of-pocket expenditures as a percentage of total health care expenditures for CSHCN were highest for dental care (55% vs. 17% for physician and 2% for hospital inpatient services) and were significantly higher than for children without SHCN (55% vs. 40%).		
Lewis et al, 2005 <sup>9</sup>	2001	To characterize CSHCN who needed dental care and from that group, those whose dental needs were not met.	78% of CSHCN were reported as needing dental care in the past 12 months, which was second only to prescription medications in the frequency of need. An estimated 755,581 or 10.4% of CSHCN who needed dental care did not receive all they needed. Relative to all other health care service categories, unmet dental care needs affected the most CSHCN.		
Van Cleave and Davis, 2008 <sup>13</sup>		use and unmet need between	CSHCN attend preventive dental visits at similar or higher rates than other children. CSHCN who had a preventive dental visit had substantially lower adjusted odds of reporting an unmet preventive dental need compared to CSHCN without a preventive dental visit. CSHCN were more likely to have dental insurance than children without SHCN (82% vs. 77%, p<0.001), however more CSHCN report an unmet preventive dental care need.		
Kenney et al, 2008 <sup>14</sup>		To compare parent-reported preventive dental care use and oral health status between children with and without SHCN.	Approximately 80% of CSHCN and 72% of children without SHCN received preventive dental care. More parents of CSHCN reported unmet preventive dental care needs compared to children without SHCN, despite greater odds of CSHCN having dental insurance and receiving preventive dental care. Fewer CSHCN parents described their children as having good/excellent dental health relative to parents of children without SHCN (67 vs. 73%, p<.001).		
Lewis, 2009 <sup>16</sup>		To determine the prevalence of toothache in US children and subgroups including CSHCN	last 6 months compared to 10% of children without SHCN (p<0.0001). Among more severely affected CSHCN, 19% were reported to have had a recent toothache.		

NHIS: National Health Interview Survey MEPS: Medical Expenditure Panel Survey

NS-CSHCN: National Survey of Children with Special Health Care Needs

NSCH: National Survey of Children's Health

Table 2

Weighted descriptive and multivariable regression results for outcome of unmet need for any dental care\*

NAME OF VARIABLE	PERCENT CSHCN WITH ANY UNMET DENTAL CARE NEED*	ADJUSTED ODDS RATIO AND 95% CONFIDENCE INTERVAL
All CSHCN (N=8.8 million)	8.9%	<del></del>
<u>Age</u> )-5 years (43.4%)	8.7%	reference
i-12 (35.7)	7.6	0.85 (0.66, 1.08)
3-17 (20.9)	10.6	1.37 (1.06, 1.76)
Race/ethnicity		
White (66.0%)	7.2%	reference
Latino (15.6)	13.8	1.27 (0.99, 1.63)
Black (11.7)	12.7	1.12 (0.92, 1.37)
Multiracial (3.7)	10.5	1.17 (0.89, 1.55)
Other (2.9)	9.1	1.34 (0.88, 2.05)
Poverty level		
= 400% FPL (30.2)	2.9% ***	reference
00-399% FPL (14.7)	4.8	1.62 (1.24, 2.12)
00-299% (16.4)	9.3	2.89 (2.29, 3.65)
50-199% (10.2)	13.9	3.95 (3.01, 5.18)
00-149% (10.9)	16.3	4. 45 (3.41, 5.80)
100% FPL (17.5%)	17.6	4.70 (3.62, 6.10)
Current Insurance		
Private (70.0%)	6.0%	reference
Public (26.4)	14.3	1.07 (0.89, 1.28)
Juinsured (3.6)	36.3	1.79 (1.31, 2.46)
at least one lapse in insurance		
luring the last year (8.9%)	29.4%	2.97 (2.38, 3.71)
Condition Severity		
Condition affects child's ability:	**	
Vot at all (38.6)	5.1%**	reference
'ery little(11.6)	8.0	1.32 (1.08, 1.61)
omewhat (26.8)	11.8	1.76 (1.48, 2.09)
great deal (22.9%)	17.1	2.59 (2.06, 3.25)
ersonal doctor or nurse		
'es (93.5%)	8.0%	reference
Vo (6.5)	16.6	1.32 (0.99, 1.76)

<sup>\*</sup> Among children said to have needed dental care

<sup>\*\*</sup> Children without special health care needs had 5% unmet dental care need

<sup>\*\*\*</sup> Significant trend both on adjusted and unadjusted analyses, p<0.0001 on all comparisons