

Dental Care and Children with Special Health Care Needs: A Population-Based Perspective

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This paper grew out of a project reviewing progress in children's oral health after *Oral Health in America: A Report of the Surgeon General* was published in 2000. 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 Children with Special Health Care Needs 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.

Dental care remains the most frequently cited unmet health need for CSHCN. More CSHCN had unmet needs for nonpreventive than preventive dental care. CSHCN who are teens, poorer, uninsured, had insurance lapses, or are 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 special health care needs. Nevertheless, CSHCN, particularly lower income and severely affected, are more likely to report unmet dental care need compared with unaffected children. Despite advances in knowledge about dental care among CSHCN, unanswered questions remain. Recommendations are provided toward obtaining additional data and facilitating dental care access for this vulnerable population.

KEY WORDS: children; dental care; disability; oral health; special health care needs

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This paper grew out of an American Academy of Pediatrics project reviewing progress in the area of children's oral health after the publication of *Oral Health in America: A Report of the Surgeon General* in 2000. 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 among CSHCN. Prior to 2000, there existed no population-based studies describing the dental care utilization or needs among CSHCN residing in the United States. When *Oral Health in America: a Report of the Surgeon General* was published that year,¹ 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 colleagues² published a sentinel paper entitled, "Access to Health Care for Children with Special Health Care Needs," relying on data from the 1994–1995 National Health Interview Survey on Disability and representing the first time that dental care was described as the leading unmet health care need among US CSHCN.

Since the article by Newacheck and colleagues,² other population-based studies have been published, furthering

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 as well as the development of a screening instrument that operationalized this definition: "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."³ 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 or not. The CSHCN screener is now a component of several national surveys, including the Medical Expenditure Panel Survey administered by the US Agency for Health Care Quality and Research,⁴ the National Survey of Children with Special Health Care Needs (NS-CSHCN),⁵ and the National Survey of Children's Health.⁶ The latter two are Maternal and Child Health Bureau–funded surveys conducted by the National Center for Health Statistics of the Centers for Disease Control and Prevention. 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. Published dental-related findings from these surveys are summarized in [Table 1](#).

The second iteration of the NS-CSHCN (2006)⁵ is the focus of this research. Some revisions since the 2001

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Table 1. Summary of Published Studies from Nationally Representative Survey*

Study and Year	Data and Year Collected	Study Objective	Dental-Related Findings
Newacheck et al, 2000 ²	NHIS† on Disability, 1995	To assess the role health insurance plays in influencing access to care and use of services by children with special health care needs	The most prevalent unmet needs were for dental care (8.1% of CSHCN‡) vs 3.2% unmet needs for medical care. Among the uninsured, CSHCN 24% had unmet dental care needs compared with 6% of insured CSHCN.
Newacheck and Kim, 2005 ¹⁵	MEPS,§ 2000	To provide the first nationally representative data on health care expenses, including out-of-pocket health care expenses for CSHCN, and to compare health care utilization and expenditures between children with and without SHCN	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%, respectively).
Lewis et al, 2005 ⁹	NS-CSHCN,¶ 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 prior 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 ¹³	NSCH,# 2003	To compare preventive dental care use and unmet need between children with and without SHCN	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%, respectively; $p < .001$); however, more CSHCN report an unmet preventive dental care need.
Kenney et al, 2008 ¹⁴	NSCH, 2003	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 with 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%, respectively; $p < .001$).
CWL, unpublished data, 2009	NSCH, 2007	To determine the prevalence of toothache in US children and subgroups, including CSHCN	15% of CSHCN had experienced a toothache in the last 6 months compared with 10% of children without SHCN ($p < .0001$). Among more severely affected CSHCN, 19% were reported to have had a recent toothache.

*Includes children with special health care needs with dental-related findings.

†NHIS = National Health Interview Survey.

‡CSHCN = children with special health care needs.

§MEPS = Medical Expenditure Panel Survey.

||SHCN = Special health care needs.

¶NS-CSHCN = National Survey of Children with Special Health Care Needs.

#NSCH = National Survey of Children's Health.

NS-CSHCN were relevant to better understanding dental care needs of CSHCN. Specifically, in the 2006 version, it is now easier to identify specific subgroups with more unmet dental care need, to separate out preventive versus "other dental care" (eg, fillings and other restorative dental care), and to make comparisons between children with and without special health care needs. Without a nonspecial needs comparison 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.

This project 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 with children without special health care needs; 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. The impact of condition severity was of particular interest, as well as whether poverty, which is known from previous work to be an independent risk factor for unmet dental care,^{9,11} 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,⁷ 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 special health care needs so that comparisons could be made between children with and without special health care needs. Data are publicly available from the NCHS/State and Local Area Integrated Telephone Survey Web site.⁷

Study Design

The 3 data files within the NS-CSHCN (screener, household, and interview). Outcome variables of interest were unmet needs 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 preventive dental care and whether he/she needed other dental care in the previous 12 months (or since birth for children aged less than 12 months).⁸ 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." Unmet need for the 3 categories of dental care (preventive, other, any) were compared between children with and without special health care needs. Additionally, the number of CSHCN with unmet need for other health care categories (eg, mental health services) were determined for comparison with unmet dental care need. The prevalence of unmet dental care need among CSHCN with select diagnoses (eg, asthma, autism, Down syndrome) was also assessed.

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?"),⁸ 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");⁸ and 3) condition severity.

Age, race/ethnicity, and insurance status categories were developed from the range of options available in the original data. Race and ethnicity were collapsed into a single variable to give 5 racial/ethnic categories: white, Latino, black, multiracial, and other. Age was categorized into 3 groups: under 6 years, 6 to 12 years, and 13 to 17 years. As in the 2001 NS-CSHCN, there was no question in the survey about dental insurance, and thus current medical insurance status was used as a proxy. Three medical insurance categories were defined: private, public, or uninsured. Condition severity was established based on parents' responses to how often the child was affected by his/her condition and 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.

Statistical Analysis

Data were analyzed with Stata software, version 10.0 (StataCorp LP, College Station, Tex). Stata survey commands and the population weights provided in the data files were used to account for the complex sampling design and to generate population level estimates. Multivariable logistic regression analysis was conducted on the outcome of unmet need for any dental care. To address

specific interest in the impact of poverty on severely affected CSHCN, a second multivariable logistic regression model was conducted, 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, income categories were collapsed into 3 groups: below 200% FPL, 200% to 399% FPL, and 400% FPL and higher. The original 4 categories of condition severity were retained. The lincom procedure in Stata was used to generate adjusted odds ratios and 95% confidence intervals from the model containing the interaction term.

RESULTS

There were 40 840 completed interviews for CSHCN and 6113 completed interviews for children in the referent sample (ie, children without special health care needs), representing 8.8 million CSHCN and 61 million children without special health care needs, 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. Preventive 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, dental care 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/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 special health care needs; too costly was the most common reason (of those with unmet dental care need—25% of CSHCN vs 38% of children without special health care needs), followed by lack of insurance (of those with unmet dental care need—22% of CSHCN vs 30% of children without special health care needs). Almost no respondents (unweighted $n = 11$) listed the need for a special health care need dentist as the reason for not being able to obtain needed preventive dental care.

A significantly higher proportion of CSHCN relative to children without special health care needs had unmet dental care needs ($P < .0001$; Figure 1). Differences were found in unmet dental need by condition severity; 20% of severely affected CSHCN had unmet *other* dental care needs compared with 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% if no impact of condition vs 15% for severely affected children). In fact,

Table 2. Weighted Descriptive and Multivariable Regression Results for Outcome of Unmet Need for Any Dental Care*

Variable	CSHCN† With Any Unmet Dental Care Need, %*	AOR (95% CI)‡
All CSHCN (N = 8.8 million)§	8.9	
Age (%)		
0–5 years (43.4)	8.7	reference
6–12 (35.7)	7.6	0.85 (0.66–1.08)
13–17 (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
300%–399% FPL (14.7)	4.8	1.62 (1.24–2.12)
200%–299% (16.4)	9.3	2.89 (2.29–3.65)
150%–199% (10.2)	13.9	3.95 (3.01–5.18)
100%–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)
Uninsured (3.6)	36.3	1.79 (1.31–2.46)
At least one lapse in insurance during the last year (8.9)	29.4	2.97 (2.38–3.71)
Condition Severity		
Condition affects child's ability		
Not at all (38.6)	5.1§	reference
Very little (11.6)	8.0	1.32 (1.08–1.61)
Somewhat (26.8)	11.8	1.76 (1.48–2.09)
A great deal (22.9)	17.1	2.59 (2.06–3.25)
Personal doctor or nurse		
Yes (93.5)	8.0	reference
No (6.5)	16.6	1.32 (0.99–1.76)

*Among children said to have needed dental care.

†CSHCN = children with special health care needs.

‡AOR = adjusted odds ratio; CI = confidence interval.

§Children without special health care needs had 5% unmet dental care need.

||FPL = federal poverty level.

¶Significant trend both on adjusted and unadjusted analyses; $P < .0001$ on all comparisons.

CSHCN who are not impacted by their condition 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), CSHCN who were adolescents (relative to less than 6-year-olds), were found to have family incomes less than 400% FPL, were uninsured, had lapsed insurance, or were more severely affected by their condition had significantly higher

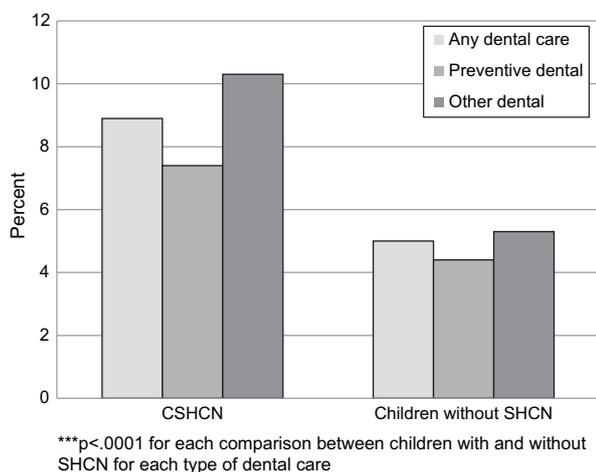


Figure 1. Percentage of children needing dental care, with and without special health care needs, who had unmet dental care need, by type of dental care. *** $P < .0001$ for each comparison between children with and without special health care needs for each type of dental care.

adjusted odds of unmet dental care need. There was a statistically significant trend for higher adjusted odds of unmet dental care need with increasing levels of poverty ($P < .0001$) and by worsening condition severity (from no impact to a great deal of impact, $P < .0001$). Results of the logistic model with the interaction term combining income relative to FPL category and condition severity demonstrated adjusted odds ratios 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 with 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 with 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).⁹ Nevertheless, there remains considerable disparity in ability to obtain needed dental 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 the 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 studies in all US children, having public insurance such as Medicaid or State Children's Health Insurance Program and one's 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. There was more unmet need for *other* dental care than for *preventive* dental care among CSHCN. Delivering preventive dental care to a CSHCN is very important; however, it is more straightforward than restorative care, which can be time-consuming and labor-intensive 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. This may help to explain why other dental care needs were less often met.

This research 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 also 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

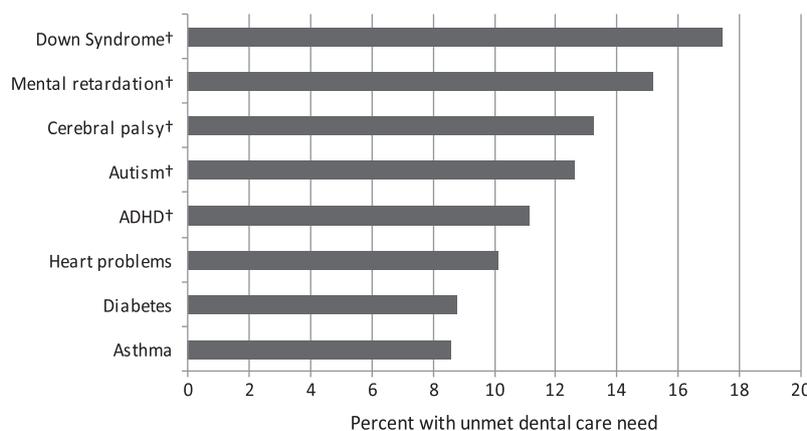
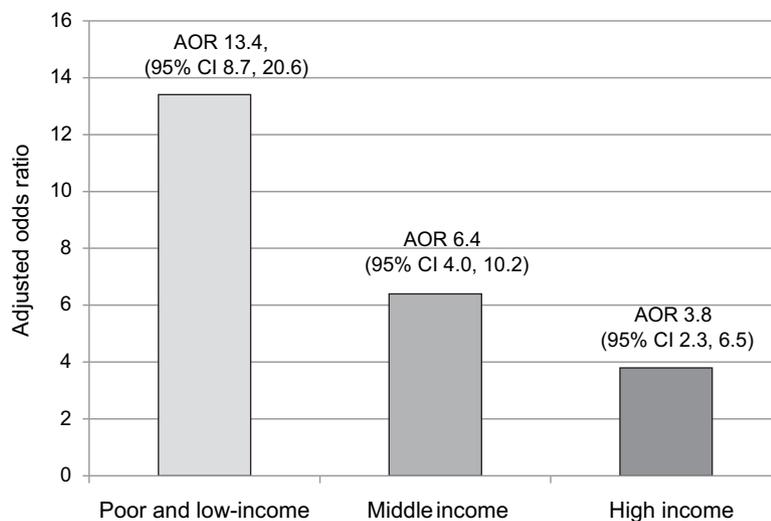


Figure 2. Percent children with special health care needs (CSHCN) with unmet dental care need by diagnosis. †Significantly different from other CSHCN; $P < .0001$. ADHD = attention-deficit/hyperactivity disorder.



†Reference category is high-income CSHCN whose condition does not impact them at all

Figure 3. Adjusted odds ratios of unmet dental care needs by income category among severely affected children with special health care needs (CSHCN). Reference category is high-income CSHCN whose condition does not impact them at all. AOR = adjusted odds ratios.

was mediated by income. This is the first time that a child's condition severity, whether considered alone or as a function of their income, has been independently related to 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 (adjusted odds ratio = 3.8 relative to other high income children who are not affected). Virtually 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. 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 remaining unanswered questions. Little is known 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. In this research, medical insurance was used as a proxy for dental coverage. But since 2.5 times as many children are uninsured for dental relative to medical care,¹⁰ this is a suboptimal substitute. Finally, differences in unmet dental care need by condition severity demonstrate the shortcoming of considering all CSHCN as

a single group. 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 has been learned about dental care for US CSHCN since release of the Surgeon General's Report in 2000. Indeed, almost everything known about this subject was gleaned from studies of the last decade. Results are remarkably consistent between studies in describing relatively equal rates of preventive dental care use by children with and without special health care needs.¹³⁻¹⁵ However, researchers have also reported more unmet dental care need^{2,9,13,14} and worse oral health among CSHCN relative to their non-special health care need peers.^{14,16} 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 with 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.^{9,16}

Despite advances in the 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, that provided preventive and restorative dental care to severely affected CSHCN within a 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 my knowledge, no one has proposed such a system. However, the degree of disparity in unmet dental care needs for severely affected children, which was 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 (eg, special education use).¹⁷ 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 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 of the impact of health problems on the family.⁸ 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. An expansion in dental-related questions in these surveys is needed.

The last 10 years have brought considerable gains in knowledge about dental care need and use among US CSHCN. These would not have been possible without efforts on the part of the Maternal and Child Health Bureau, Agency for Health Care Quality and Research, Centers for Disease Control and Prevention, and National Center for Health Statistics 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 the

goal of better understanding the dental care needs of CSHCN and of developing systems of care to meet these needs.

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