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*Pediatrics* 2005;116:e426-e431

DOI: 10.1542/peds.2005-0390

The online version of this article, along with updated information and services, is  
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<http://www.pediatrics.org/cgi/content/full/116/3/e426>

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# Unmet Dental Care Needs Among Children With Special Health Care Needs: Implications for the Medical Home

Charlotte Lewis, MD, MPH\*‡; Andrea S. Robertson, MPH\*; and Suzanne Phelps, MS\*

**ABSTRACT.** *Background.* Little is known about the characteristics of children with special health care needs (CSHCN) who have unmet dental care needs.

*Objective.* We sought to describe the magnitude of unmet needs for dental care among CSHCN and to characterize those with unmet dental care needs.

*Design, Setting, and Subjects.* We used data from the National Survey of Children with Special Health Care Needs, which used a telephone survey to identify 750 CSHCN from each of the 50 states and the District of Columbia. Families of 38 866 CSHCN were interviewed, and the data were weighted to represent 9.32 million CSHCN nationally.

*Outcome.* Our primary outcome of interest was unmet dental care need, defined as whether CSHCN were said to have needed dental care but were unable to obtain it. We also considered reasons why a child had an unmet dental care need and compared other categories of health care service needs and unmet needs with dental care. Bivariate and multivariate analyses were conducted to determine factors associated with unmet dental care needs.

*Results.* Overall, 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. Of those who reported a dental care need, an estimated 755 581 or 10.4% of CSHCN did not receive all of the dental care they needed. Relative to all other health care service categories, unmet dental care needs affected the most children. Poorer children, uninsured children, children with lapses in insurance, and children with greater limitations attributable to disability had significantly greater odds of unmet dental care needs in multivariate analyses. Children with a personal doctor or nurse were significantly less likely to have unmet dental care needs.

*Conclusions.* Dental care is the most prevalent unmet health care need for CSHCN, affecting substantially more children than any other health care need category. Moreover, the perceived need for dental care for CSHCN exceeds the need for either preventive or specialty medical care. Given these findings, dental care should be an integral and explicitly stated part of the comprehensive coordinated services that the medical home aims to provide for CSHCN. Greater efforts to improve access to dental care for poor and more disabled CSHCN are needed. *Pediatrics* 2005;116:e426–e431. URL: [www.pediatrics.org/cgi/doi/10.1542/peds.2005-0390](http://www.pediatrics.org/cgi/doi/10.1542/peds.2005-0390); dental, access, children with special health care needs.

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ABBREVIATIONS. CSHCN, children with special health care needs; FPL, federal poverty level; MSA, metropolitan statistical area; MCHB, Maternal and Child Health Bureau.

An estimated 12% to 18% of children in the United States have special health care needs, defined as the presence of a chronic physical, developmental, behavioral, or emotional condition and a need for health care services beyond what is required by children in general.<sup>1,2</sup> Population-based studies in the past 15 years have identified dental care as a leading unmet health care need among children in general<sup>3,4</sup> and children with disabilities.<sup>2</sup> However, little is known about the characteristics of children with special health care needs (CSHCN) who have unmet dental care needs. In fact, very few data exist to describe the oral health status or dental care needs of CSHCN. However, studies of select populations, such as Special Olympics participants,<sup>5,6</sup> suggest that CSHCN have both more dental problems and more untreated dental disease, relative to children in general. Moreover, anecdotal information from health care providers and families suggests that children with chronic health problems, particularly those who are significantly impaired, encounter additional barriers to accessing dental care because of their underlying disabilities. Although substantial efforts have been made to develop coordinated comprehensive systems of health care for CSHCN through the medical home concept,<sup>7–9</sup> these have emphasized primarily preventive and specialty medical care and community and educational services, with little attention given to dental care. In this study, we used the Maternal and Child Health Bureau (MCHB) National Survey of Children with Special Health Care Needs<sup>10</sup> to describe the magnitude of unmet needs for dental care among CSHCN and to characterize more completely those with unmet dental care needs, so that strategies to improve access to dental care for this population can be developed.

## METHODS

### Data

This study was approved by the Human Subjects Division of the University of Washington. The National Survey of Children with Special Health Care Needs was a MCHB-funded survey conducted over a 2.5-year period beginning in April 2000. The primary goals of the survey were to determine the prevalence of

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Accepted for publication Apr 8, 2005.

doi:10.1542/peds.2005-0390

No conflict of interest declared.

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special needs among children nationally and to determine the adequacy of insurance, ability to access services, degree that care was coordinated, and satisfaction with care for this population.<sup>10</sup> This survey used the ongoing State and Local Area Integrated Telephone Survey, sponsored by the Centers for Disease Control and Prevention, to identify 750 CSHCN from each of the 50 states and the District of Columbia.

Children were determined to have special health care needs with a previously validated CSHCN screener instrument based on the aforementioned MCHB definition of CSHCN.<sup>11</sup> The screener is not condition specific and includes 5 stem questions on general health care needs that are potential consequences of a chronic health problem. Follow-up questions determine whether the health care needs are the result of a medical, behavioral, or other health condition and whether the condition has lasted or is expected to last for  $\geq 12$  months. Those with affirmative answers to the stem questions and both follow-up questions are classified as having a special health care need.<sup>10</sup> Among the 372 174 households reached, 38 866 CSHCN were identified for additional data collection.

## Study Design

We used data from 3 data files included in the National Survey of Children with Special Health Care Needs, i.e., screener, household, and interview. Our outcome variables of interest were (1) whether a child needed dental care (including check-ups) in the past 12 months, (2) whether he or she received the dental care if he or she needed it, and, (3) if the child needed care but did not receive it, the reported reasons for this. Children who were reported to need dental care but did not receive it were classified as having unmet dental care needs. We also assessed the prevalence of unmet dental care needs among 2 subpopulations of CSHCN of interest, ie, those in families with incomes  $< 200\%$  of the federal poverty level (FPL) and those who were usually or always limited by their underlying conditions.

For comparison with dental care, we determined the percentage of CSHCN who reported needing other categories of health care services (such as specialty medical care or prescription medications). In calculating the proportion of children with unmet needs for a particular service, the survey included only children who reported a need for the service in the denominator. Because the denominator varied for each category of service, we compared absolute numbers of children with unmet needs across health care service categories.

Covariates examined in bivariate and logistic regression analyses for their relationship to unmet dental care needs were chosen on the basis of a priori hypotheses and included variables in the following 4 categories: (1) sociodemographic characteristics, ie, child's race, Hispanic ethnicity, gender, whether the interview was conducted in a language than English, mother's education, and family income relative to the FPL; (2) health care, ie, type of health insurance, lapsed insurance in the past year, and having a regular doctor or nurse who "knew the child with a SHCN best"; (3) disability, how often, during the previous 12 months, the child's behavioral, emotional, or other health conditions affected his or her ability to do things, compared with children of the same age (subsequently referred to as "limitation attributable to disability"); and (4) residence, ie, US geographic region and metropolitan statistical area (MSA). For our analyses, we developed age, race, and insurance status categories from the range of options available in the original data. In addition to white and black race, we combined "multiracial" and "other race" into 1 group. Hispanic ethnicity was considered as a separate variable. Age was categorized into 0 to 4, 5 to 10, and 11 to 17 years of age, because we hypothesized that CSHCN in the 2 extremes of the pediatric age range would have more difficulty obtaining dental care. In our experience, very young children may not be accepted into dental offices and older children with special needs can be physically challenging to manage in the dental office if they have behavioral issues or are physically impaired.

For insurance status, we categorized each child's medical insurance status at the time of the interview into 1 of 5 groups, ie, private insurance, Medicaid, other public insurance, other insurance, or uninsured. For children with  $> 1$  category of medical insurance, we developed a hierarchy of insurance to assign a single insurance category to each child for subsequent analyses. This hierarchy was developed to prioritize assignment of a health

insurance category that included dental care as one of its benefits. Medicaid, through the Early and Periodic Screening, Diagnosis, and Treatment program, includes dental care as a mandated benefit.<sup>12</sup> Therefore, CSHCN with Medicaid were classified as having Medicaid even if they had other insurance. Public insurance other than Medicaid (Indian Health Services, Title V, or other public insurance or a State Children's Health Insurance Program) was considered as a separate category (other public insurance) because these programs do not mandate dental coverage consistently. Children were classified as having private insurance if they had private (including health maintenance organization) insurance or military coverage and did not have Medicaid. Children were classified into the other insurance category if they had other insurance, unknown insurance, or a single service plan listed and did not have Medicaid or private insurance. Children were classified as uninsured if they did not have any health insurance of any kind at the time of the interview. A separate variable for lapse in insurance during the previous 12 months was included in our analyses.

Using methods described by Mayer et al,<sup>1</sup> we assigned a MSA status to states where it had been suppressed to protect confidentiality in the original data. MSA was recoded from missing to non-MSA for states with small MSA samples, ie, most subjects lived in non-MSA or more rural locations (Alaska, Idaho, Maine, Montana, North Dakota, South Dakota, Vermont, and Wyoming). Similarly, MSA status was recoded from missing to MSA for states with small non-MSA samples (Connecticut, Delaware, Hawaii, Massachusetts, Maryland, New Hampshire, Nevada, and Rhode Island).

## Analyses

Data were analyzed with Stata software, version 8.0 (Stata Corp, College Station, TX). We used Stata survey commands and the population weights provided in the data files to account for the State and Local Area Integrated Telephone Survey design for all of our analyses. Bivariate analyses were conducted to assess the relationships between the outcome variable, unmet dental care needs, and each of the covariates specified above. Logistic regression analyses were performed to assess the independent associations between unmet dental care needs and the covariates of interest.

## RESULTS

The 38 866 CSHCN identified for interviews were weighted to represent 9.32 million CSHCN nationally. Overall, 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 (Fig 1). Of those who reported dental care needs, an estimated 755 581 or 10.4% of CSHCN did not receive all of the dental care they needed. Relative to all other health care service categories, unmet dental care needs affected the most children and 78% more children than mental health care, which was the second most common unmet need (Fig 2). Characteristics of CSHCN according to their met or unmet dental care need status are presented in Table 1.

When asked why the CSHCN did not receive needed dental care, the leading reason was excess cost, with 42% citing this reason. The second most common reason was a "health plan problem" (defined as a noncovered benefit or an inability to obtain insurance company approval), which was cited by 26%. Other reasons for unmet dental care needs included "not convenient time" (10.1%), "not available in area/transport problem" (5.0%), "doctor did not know how to treat or provide care" (2.7%), and "other reason" (14.3%). Unmet dental care needs were greater among poor and more disabled children; among CSHCN at  $< 200\%$  of the FPL, 21% had

Fig 1. Percentage of CSHCN reporting needs in each category of care surveyed (N = 9.32 million). OT indicates occupational therapy; PT, physical therapy.

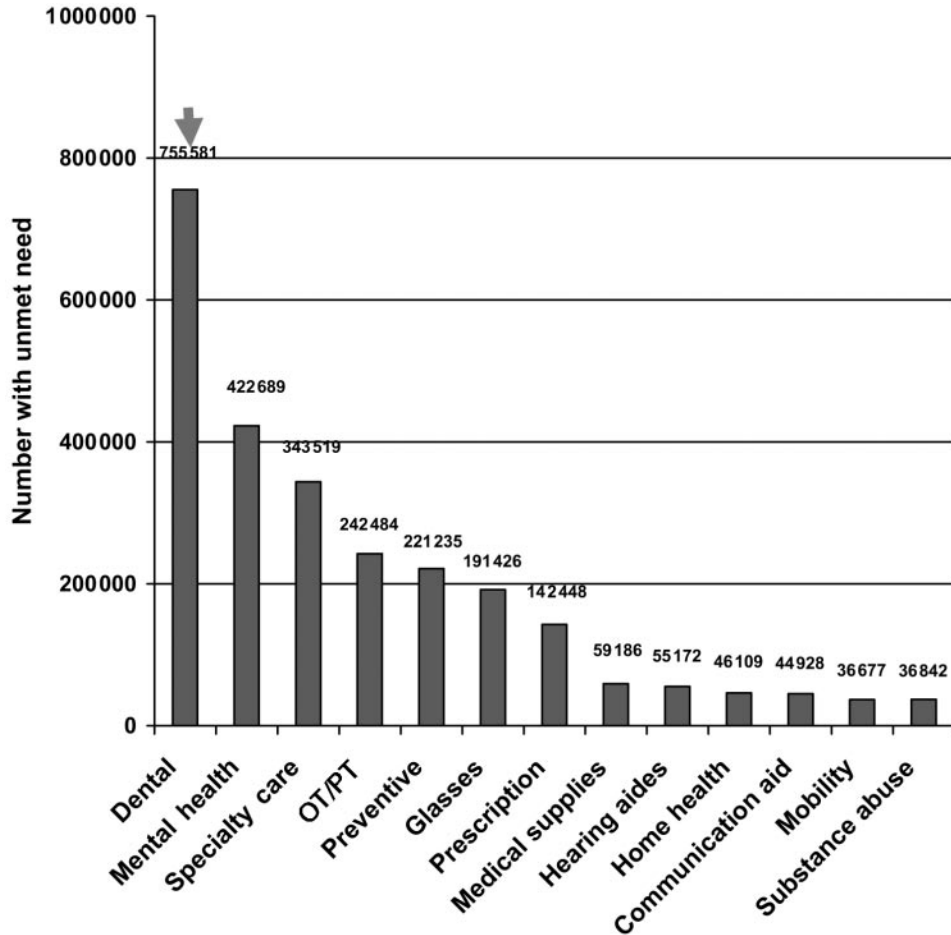
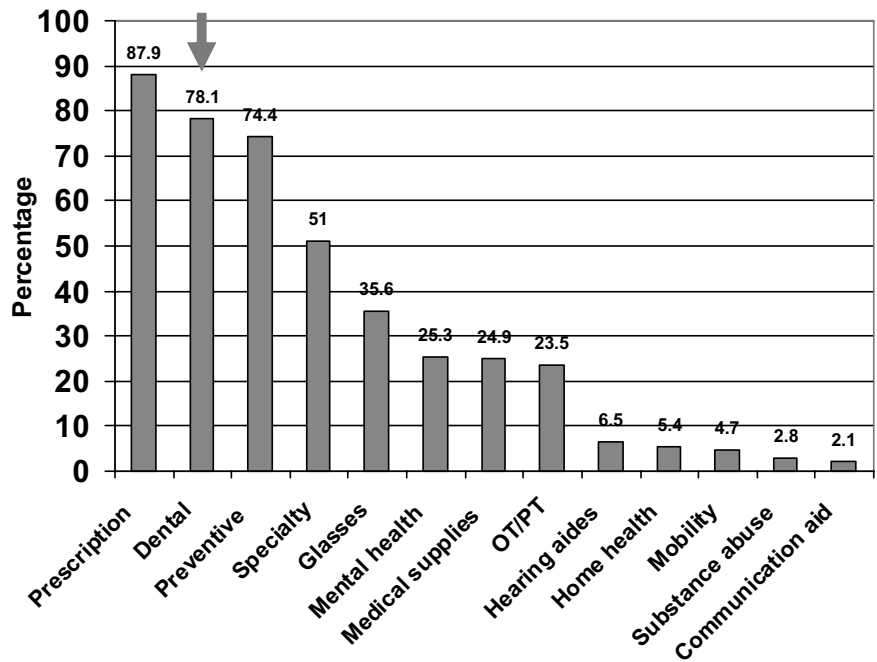


Fig 2. Prevalence of unmet needs in each category of care surveyed (N = 9.32 million).

unmet dental care needs, and among those who were usually or always limited by their condition, 32% had unmet dental care needs.

When covariates were examined independently

for their relationship to unmet dental care needs, with logistic regression analyses (Table 2), the following variables were associated with greater unmet dental care needs: (1) being in the oldest age group,

**TABLE 1.** Characteristics of CSHCN According to Unmet Dental Care Need Status (Weighted Data, *N* = 9.32 Million)

Variable	Unmet Dental Care Need, %	
	No (89.6%)	Yes (10.4%)
Age		
0–4 y (reference)	8.2	9.1
5–10 y	40.0	35.1
11–17 y	51.8	55.8
Female*	40.3	45.4
Race		
White (reference)	78.3	64.7
Black*	12.9	20.5
Multiracial/other*	8.8	14.8
Hispanic ethnicity*	9.9	16.4
Mother's education		
8th grade or less*	2.0	6.7
Some high school*	8.9	21.0
High school*	28.9	30.0
Post-high school*	32.7	30.9
College or more (reference)	27.5	11.4
Non-English interview*	2.2	7.6
Percent of FPL		
≥400 (reference)	34.6	9.0
300 to <400 *	18.2	10.5
200 to <300*	18.1	16.8
100 to <200*	18.3	36.1
<100*	10.8	27.6
Insurance type*		
Private (reference)	73.5	42.0
Medicaid*	21.6	34.4
Other public*	1.8	4.6
Other*	0.3	0.6
Uninsured*	2.8	18.5
Lapsed insurance in past year*	6.9	36.0
Regular doctor†	91.1	80.0
How often limited by disability		
Never (reference)	42.0	22.1
Sometimes*	38.6	47.2
Usually*	7.8	12.4
Always*	11.6	18.3
Resides in MSA†	82.1	78.1
Region		
Northeast (reference)	19.5	13.7
Midwest	23.2	17.1
South*	35.8	46.0
West*	21.4	23.2

\* Significantly associated with greater unmet dental care need, relative to reference category, in bivariate analysis.

† Significantly associated with lesser unmet dental care need, relative to reference category, in bivariate analysis.

relative to the 0- to 4-year age group; (2) lower income, relative to the FPL; (3) lapsed insurance; (4) being uninsured or having other insurance, relative to private insurance; (5) southern or western US residence, compared with northeastern residence; and (6) more frequent limitation attributable to disability. Having a regular doctor or nurse who knew the CSHCN best was associated with significantly lower odds of unmet dental care needs, even after controlling for potentially confounding variables. Race, Hispanic ethnicity, Medicaid or other public insurance (relative to private insurance), non-English interview, gender, and MSA were not associated significantly with unmet dental care needs after controlling for the other covariates in the model. Relative to incomes >400% of the FPL, all of the lower income categories were associated significantly with unmet dental care needs. There were significant dose-response relationships ( $P < .001$  for trend) of both

income category and degree of limitation with unmet dental care needs in the adjusted analyses (Fig 3).

## DISCUSSION

Unlike previous health care need assessment studies that inquired only about unmet needs, the National Survey of Children with Special Health Care Needs included questions about both whether a service was needed and, if so, whether it could be obtained. Our findings indicate that dental care is considered a leading health care need, second only to prescription medication needs, and that dental care needs exceed perceived needs for preventive and specialty care among CSHCN. Furthermore, dental care is the leading unmet health care need for CSHCN, with more than three quarters of a million CSHCN nationally being unable to obtain needed dental care.

Among those with a perceived need for dental care, 10.4% of CSHCN were unable to obtain dental care. The prevalence of unmet dental care needs found here is higher than findings of other studies of unmet needs among children in general and CSHCN. Newacheck et al found that 5.3% of children overall in the 1993 to 1996 National Health Interview Survey<sup>3</sup> and 8.1% of CSHCN in the 1994 to 1995 National Health Interview Survey on Disability<sup>2</sup> had unmet dental care needs. Whether these differences represent an increase in unmet dental care needs among CSHCN over time or reflect methodologic differences in study designs is not known.

Although other studies have described dental care as a frequently cited unmet need, ours is the first to characterize CSHCN who had unmet dental care needs. Although being uninsured was associated significantly with unmet dental care needs, children with Medicaid and those with other public insurance did not have significantly greater unmet dental care needs, compared with those with private insurance, after controlling for other covariates. This may be because dental benefits are included in many public insurance programs, but it also suggests that other barriers associated with greater degrees of poverty or disability independently influence the ability to obtain needed dental care. In fact, our findings indicated that poor and nearly poor CSHCN and those with greater limitations attributable to disability were more likely to have unmet dental care needs, even after adjustment for potential confounders (Fig 3). Factors associated with unmet dental care needs among CSHCN are similar to those associated with unmet needs for routine and specialty medical care,<sup>1</sup> which emphasizes the importance of ongoing advocacy for health and dental care access for low-income CSHCN.

In contrast to our hypothesis that younger children would have more difficulty accessing dental care, compared with school-aged children, children <5 years of age were least likely to have an unmet dental care need. This might be because most young children have not had time to develop dental problems that would require anything more than routine dental care. Older CSHCN might have more complex dental care needs, medical comorbidities, or behav-

**TABLE 2.** Multivariate Logistic Analyses of Unmet Dental Care Needs (Weighted Analyses)

Variable	Adjusted Odds Ratio* (95% Confidence Interval)
Age	
≤4 y (reference)	1.00
5–10 y	1.00 (0.72–1.39)
11–17 y	1.37 (1.00–1.87)
Percent of FPL†	
≥400 (reference)	1.00
300 to <400	1.91 (1.22–2.99)
200 to <300	2.53 (1.69–3.78)
100 to <200	3.97 (2.64–5.98)
<100	4.51 (2.83–7.19)
Insurance type	
Private (reference)	1.00
Medicaid	0.96 (0.74–1.25)
Other public	1.44 (0.91–2.27)
Other	1.03 (0.17–6.37)
Uninsured	1.61 (1.06–2.46)
Lapsed insurance in past year (relative to not lapsed)	3.62 (2.73–4.81)
Regular doctor (relative to no regular doctor)	0.59 (0.46–0.77)
How often limited by disability†	
Never (reference)	1.00
Sometimes	1.69 (1.35–2.12)
Usually	1.79 (1.33–2.41)
Always	2.28 (1.70–3.06)
Region	
Northeast (reference)	1.00
Midwest	1.06 (0.81–1.39)
South	1.60 (1.24–2.06)
West	1.41 (1.03–1.93)

\* Model also adjusted for gender, race, Hispanic ethnicity, MSA, non-English interview, and mother's education.

† Significant trend test,  $P < .001$ .

ior management issues that would make it difficult to find a dentist willing to provide care.

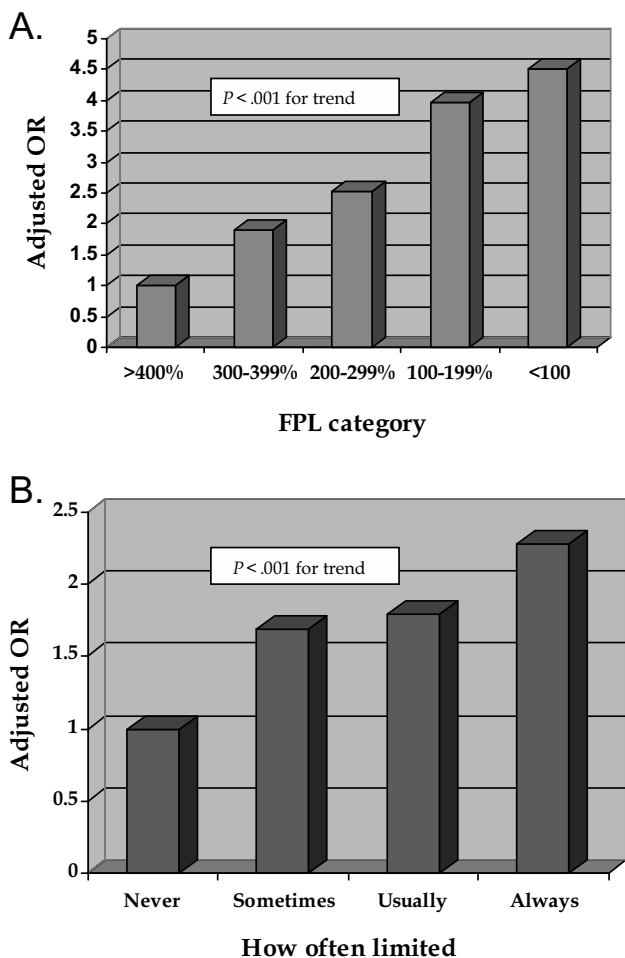
We found that having a regular doctor or nurse was significantly protective against an unmet dental care need. This relationship persisted even after controlling for other covariates potentially associated with having a regular source of care, including income, insurance, and maternal education. It may be that there are other unmeasured factors that influence the relationship between having a regular doctor or nurse and receiving needed dental care. However, it is also possible that health care providers enable access to dental care for CSHCN through referrals and other means. To our knowledge, no previous study has attempted to assess the degree to which primary care providers influence access to dental care for CSHCN, although oral health assessment and dental referral are required under the Early and Periodic Screening, Diagnosis, and Treatment program.<sup>12</sup>

The finding that having a regular doctor or nurse promotes receipt of dental care points to the importance of identifying a regular and personal source of health care for all CSHCN. Indeed, a central tenet of the medical home concept is that children have a personal physician.<sup>7</sup> The medical home is considered so important for CSHCN that the US Department of Health and Human Services included, in their Healthy People 2010 goals and objectives, the goal that "all children with special health care needs will receive regular ongoing comprehensive care within a medical home."<sup>7</sup> To date, however, relatively little attention has been paid to incorporating dental care

into the comprehensive coordination of care and services that the medical home aims to provide. For example, the 2002 American Academy of Pediatrics policy statement on the medical home describes comprehensive health care as encompassing acute and chronic medical care, preventive care, subspecialty medical care, and surgical care but makes no mention of dental care.<sup>7</sup> The absence of dental care on a list of comprehensive health care services that CSHCN should receive may have its roots in the historically separate traditions of medical and dental training, insurance, and systems of care. Nevertheless, given the degree to which CSHCN perceive the need for dental care and fail to receive this needed care, as documented in this study, this seems to be a substantial oversight.

Dental care should be an explicit and integral part of coordinated comprehensive care facilitated by the medical home, in much the same way that subspecialty medical care and surgical care are; that is, the medical home identifies the need for dental care, refers the patient to an appropriate site for care, advocates for access to dental care, and coordinates care and communication between the dental provider, the family, and the primary care physician. Under our current paradigm, families may be reminded by the primary care physician to seek dental care, but little attention is paid subsequently to whether the child actually receives dental care. Clearly, our results indicate that many CSHCN, particularly those with greater degrees of disability and poverty, are unable to obtain the dental care they need.

Certain caveats bear consideration. The MCHB



**Fig 3.** Adjusted odds ratios for unmet dental care needs according to income (A) and how often the child is limited by the condition (B).

definition of CSHCN used in this survey, as broad as it is, might include a number of children who require more health care services but do not have any definable disability that would affect their ability to obtain dental care. It is important to keep in mind that specific conditions may not be as important as the degree of disability in predicting unmet dental care needs. For example, children with mild asthma may receive services at a greater level than do children in general and thus may be classified as having special needs. However, mild asthma may not impose additional barriers to receiving dental care. Severe asthma that always limits a child's activities may indeed make it more difficult to find a dentist who is comfortable providing dental care. Similarly, children with mild cerebral palsy may have no difficulty securing dental care, whereas children with severe cerebral palsy may encounter significant barriers to obtaining dental care because of their degree of disability. Whether CSHCN who have little or no limitation of their activities attributable to their underlying condition have any greater difficulties obtaining dental care, compared with their peers without special needs, could not be ascertained from this survey, because it was limited to CSHCN. However, relying on the variable of the degree of limitation attributable to disability allowed us to confirm that, among

CSHCN as defined by MSHB, greater limitation predicted independently higher odds of unmet dental care needs.

Other limitations should also be mentioned. As with other interview studies focused on children, reliance on parental reports to determine needs may not reflect accurately the true needs of the child. In addition, there is the potential for misclassification of some variables, most notably insurance. Only medical insurance status was obtained during the data collection. Medical insurance is not an exact proxy for dental insurance status and, in fact, children are 2.5 times more likely to lack dental insurance than to lack medical insurance.<sup>13</sup> It may be that more children were uninsured for dental care than our results reflect and that we underestimated the effect of being uninsured by relying only on medical insurance status.

## CONCLUSIONS

We have determined that dental care is the most prevalent unmet health care need for CSHCN. Moreover, the perceived need for dental care for CSHCN exceeds needs for either preventive or specialty medical care. Greater degrees of poverty and limitation attributable to disability pose independent risks for unmet dental care needs. However, having a regular doctor or nurse who knows the CSHCN seems to protect against unmet dental care needs, which points to the importance of considering dental care among the comprehensive coordinated services that a medical home aims to provide.

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