

# Respite Care for Children With Special Health Care Needs

Savithri Nageswaran, MD, MPH

**Objectives:** To describe (1) the subpopulation of children with special health care needs (CSHCN) in need of respite care and (2) the factors associated with unmet respite care needs.

**Design:** Cross-sectional study using the 2001 National Survey of Children With Special Health Care Needs.

**Setting:** The United States.

**Participants:** Caregivers of CSHCN.

**Main Outcome Measures:** We determined the association of sociodemographic factors and health status of CSHCN with need for respite care and unmet needs for respite care.

**Results:** Of the 38831 respondents, 3178 (8.8%) reported need for respite care in the prior 12 months. The CSHCN who were young and uninsured/had insurance gaps or had public insurance and those with functional

limitations and unstable health conditions were more likely to need respite care. Twenty-four percent of CSHCN who needed respite care did not receive such services. In multivariate analysis, higher maternal education (adjusted odds ratio [AOR], 1.6 for more than high school education compared with high school education or less), some and severe functional limitations (AORs, 2.5 and 5.6, respectively, compared with no limitation), and unstable health condition (AOR, 2.3 compared with stable condition) were associated with greater unmet respite care needs. The CSHCN with public insurance were half as likely and CSHCN with private insurance were as likely to report unmet respite care needs as those who were uninsured/with insurance gaps.

**Conclusions:** Respite care needs of CSHCN are frequently unmet. Furthermore, strategies are needed to improve access to respite care for families of CSHCN.

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**C**HILDREN WITH SPECIAL health care needs (CSHCN) are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.<sup>1</sup> There are an estimated 9.3 million CSHCN in the United States, accounting for 14% to 18% of all children nationwide.<sup>2,3</sup>

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Care of CSHCN strains the physical, emotional, mental, financial, and social well-being of caregivers.<sup>4-6</sup> Families are the largest providers of long-term care for children with disabilities.<sup>7</sup> Long-term medical care of children with complex conditions can be overwhelming and can lead to poor psychological outcomes in caregivers.<sup>8-13</sup> To provide optimal care for CSHCN in the community, families need adequate psychological and social sup-

port. The American Academy of Pediatrics recommends support services such as respite care for families of CSHCN.<sup>14</sup>

Respite care seeks to decrease the burden on caregivers by giving them a break in caring for their CSHCN. Parents rank respite care as one of the most needed services for families caring for CSHCN,<sup>15,16</sup> and studies suggest that respite care improves well-being of parents/caregivers of CSHCN.<sup>17-19</sup> Yet, respite needs of caregivers of CSHCN are frequently unmet.<sup>20,21</sup> Population-based studies with a primary focus on respite care are lacking. Using a large nationally representative sample of CSHCN, we sought to determine the sociodemographic and health status characteristics that are associated with need for respite care and unmet needs for respite care among CSHCN.

## METHODS

### DATA SOURCE

We used cross-sectional data from the 2001 National Survey of Children With Special Health Care Needs (NSCSHCN), which was sponsored by the Maternal and Child Health Bu-

**Author Affiliations:**  
Departments of Pediatrics and Social Sciences and Health Policy, Wake Forest University School of Medicine, Winston-Salem, North Carolina.

reau.<sup>22</sup> The survey was conducted by the National Center for Health Statistics between October 2000 and April 2002 in the United States. The survey used a random-digit-dial sample of households with children younger than 18 years from each state and the District of Columbia.<sup>22</sup> All survey data are publicly available at the National Center for Health Statistics Web site.<sup>23</sup>

Respondents in this survey were parents or guardians who were most knowledgeable about the child's condition. The response rate was 61%. The sample is weighted for nonresponse, telephone lines, and 2000 census characteristics. Children were identified as having special health care needs using the CSHCN Screener, which is a validated tool to identify CSHCN.<sup>22,24</sup> The CSHCN Screener has 14 items inquiring about a condition that has lasted or is expected to last a year or longer and results in the need for medical and other services, special therapies, prescription medicines, limitation of ability, or an emotional, behavioral, or developmental condition needing counseling.<sup>25</sup> Prior studies have described the characteristics of CSHCN in the NSCSHCN.<sup>6,26,27</sup>

## DEPENDENT VARIABLES

"Respite care need" and "unmet respite care" were the dependent variables of interest. Both were dichotomous variables. Respite care need was derived from the question in the survey that asked whether the caregiver or his or her family needed respite care in the 12 months prior to the survey (response options: yes/no). Respite care was further explained to families as having someone care for the child so that the caregiver could do other things. Respondents who reported a need for respite care were asked whether they received all the respite care that they needed (response options: yes/no); those who responded no to this question were considered to have an unmet respite care need. Finally, respondents who reported unmet respite care needs were asked if this stemmed from lack of availability/transportation problems, cost, health plan problem, inconvenient time, or other reasons.

## INDEPENDENT VARIABLES

Age, sex, metropolitan status of residence, maternal education, income level of the household, insurance type, race/ethnicity, functional limitation of the child, and stability of the child's condition were the independent variables. All the independent variables were categorical. We categorized age into younger than 6 years, 6 years through 11 years, and 12 through 17 years. Maternal education level was categorized into high school or less and more than high school. Income level of the household was categorized into income less than 100% of the federal poverty level (FPL), 100% to 199% of the FPL, 200% to 399% of the FPL, and 400% of the FPL or more. Insurance type was classified into uninsured/had gaps in insurance in the year prior to the survey, public, private, and other insurance types. Race/ethnicity had 4 categories: non-Hispanic white, non-Hispanic black, Hispanic, and other. We derived the functional limitation variable from 2 questions that asked how often and how much the child's condition affects his or her ability to do things his or her peers could do and categorized it into severe, some, and no limitation. Stability of the child's condition had 3 categories and was derived from the question that asked whether the child's health care needs changed all the time (unstable), once in a while (less stable), or was usually stable.

## STATISTICAL ANALYSIS

We performed bivariate analyses between the dependent variables (respite care need and unmet respite care) and the inde-

pendent variables. We used Pearson  $\chi^2$  test to examine the associations between categorical variables. In multivariate analyses, we examined the association of independent variables with respite care need and unmet respite care in 2 logistic regression models. To obtain population-level estimates, appropriate survey weights were used in the analyses. A *P* value of less than .05 was considered to be statistically significant. Stata Intercooled version 8.2 (StataCorp, College Station, Texas) was used for statistical analyses. The institutional review board of Wake Forest University Health Sciences approved the study.

## RESULTS

### RESPITE CARE NEED

Of the 38 866 participants in the NSCSHCN, 38 831 (99.9%) responded to the question from which the "respite care need" variable was derived. Of the respondents, 3178 (8.8%) reported a need for respite care in the 12 months prior to the survey.

The results of bivariate analysis of respite care need with sociodemographic and health status factors are presented in **Table 1**. Need for respite care was higher among CSHCN of younger age, low maternal education, low-income households, and minority race/ethnicity. The CSHCN with private insurance were less likely to report need for respite care compared with CSHCN who were uninsured/with insurance gaps and those with public insurance and other insurance types. Respite care need increased as functional limitations of CSHCN increased, and CSHCN with unstable health conditions were most likely to report need for respite care.

In multivariate analysis, age, insurance type, functional limitations, and stability of the child's condition were significantly associated with the need for respite care (**Table 2**). Children younger than 6 years were 3 times as likely and those between 6 through 11 years of age were twice as likely to need respite care as children 12 through 17 years of age. Children with private insurance were half as likely as those without health insurance/with gaps in insurance to need respite care. There was no difference between children who were uninsured/had insurance gaps and those with public insurance in the need for respite care. Children with some functional limitations and those with severe limitations were 2 and 4 times more likely to report respite care need, respectively, than those without functional limitation. Compared with caregivers of CSHCN with a stable health condition, caregivers of those whose health condition was unstable were twice as likely to need respite care. Maternal education, household income, and race/ethnicity were not associated with respite care need in multivariate analysis.

### UNMET RESPITE CARE NEEDS

Twenty-four percent (774 of 3163 respondents) of caregivers of CSHCN who needed respite care reported that their needs were unmet. In bivariate analysis, CSHCN whose mothers had more than high school education had greater unmet needs for respite care than those whose mothers had high school education or less. Thirty-three percent of CSHCN who were uninsured/had gaps in in-

**Table 1. Respite Care Need by CSHCN Characteristic**

Characteristic	Respite Care Need, %	P Value
Age, y		<.001
12-17	5	
6-11	10	
<6	14	
Sex		.02
F	8	
M	9	
Residence		.11
Rural	10	
Urban	9	
Maternal education		.003
≤High school	10	
>High school	8	
Household income, % of FPL		<.001
>400	5	
200-399	8	
100-199	12	
<100	15	
Insurance type		<.001
Uninsured/gaps in insurance	13	
Public	16	
Private	4	
Other	14	
Race/ethnicity		<.001
Non-Hispanic white	7	
Non-Hispanic black	14	
Hispanic	10	
Other	12	
Functional limitations		<.001
None	4	
Some	8	
Severe	19	
Stability of condition		<.001
Usually stable	7	
Less stable	10	
Unstable	22	

Abbreviations: CSHCN, children with special health care needs; FPL, federal poverty level.

insurance, 24% of those with private insurance, and 22% of those with public insurance had unmet needs for respite care. As functional limitations of CSHCN increased, the proportions of CSHCN with unmet respite care need increased. While 20% of CSHCN with stable health conditions had unmet respite care needs, this was doubled for those whose condition was unstable (**Table 3**).

In multivariate analysis, maternal education, insurance type, child's functional limitation, and stability of the child's condition were associated with unmet respite care needs (**Table 4**). The CSHCN with public insurance or other insurance were half as likely as those who were uninsured/had insurance gaps to report unmet respite care needs. There was no difference between CSHCN who were uninsured/had gaps in insurance and those with private insurance in unmet respite care needs. The CSHCN with severe functional limitations were 6 times as likely and those with some limitations were 3 times as likely as those with no limitation to have unmet respite care needs. The CSHCN with a health condition that was unstable were twice as likely

**Table 2. Adjusted Odds Ratios for Respite Care Need<sup>a</sup>**

Characteristic	Odds Ratio (95% Confidence Interval)
Age, y	
12-17	1 [Reference]
6-11	2.1 (1.7-2.5)
<6	3.2 (2.6-4.0)
Sex	
F	1 [Reference]
M	1.2 (1.0-1.4)
Residence	
Rural	1 [Reference]
Urban	1.0 (0.8-1.2)
Maternal education	
≤High school	1 [Reference]
>High school	1.2 (1.0-1.4)
Household income, % of FPL	
>400	1 [Reference]
200-399	1.2 (0.96-1.6)
100-199	1.1 (0.8-1.5)
<100	1.1 (0.7-1.5)
Insurance type	
Uninsured/gaps in insurance	1 [Reference]
Public	1.1 (0.8-1.4)
Private	0.4 (0.3-0.6)
Other	1.1 (0.8-1.5)
Race/ethnicity	
Non-Hispanic white	1 [Reference]
Non-Hispanic black	1.4 (1.1-1.8)
Hispanic	1.1 (0.9-1.5)
Other	1.1 (0.8-1.5)
Functional limitations	
None	1 [Reference]
Some	1.6 (1.3-2.0)
Severe	3.7 (3.0-4.7)
Stability of condition	
Usually stable	1 [Reference]
Less stable	1.3 (1.1-1.6)
Unstable	1.9 (1.4-2.5)

Abbreviation: FPL, federal poverty level.

<sup>a</sup>Adjusted in multivariate analysis for all other variables in the Table.

to report unmet respite care needs as those with a stable health condition. However, there was no difference in unmet respite care needs between those with stable or less stable conditions.

Of those who reported unmet respite care needs, 767 described the reasons for unmet respite care needs. Twenty-six percent reported lack of availability or transportation problems, 22% reported too much cost, 13% reported health plan problem, 7% reported that time was not convenient, and 18% listed other unspecified reasons.

#### COMMENT

To our knowledge, this is the first population-based study to describe respite care needs and unmet needs for respite care among families with CSHCN. Our study shows that 9% of CSHCN need respite care; of those, 25% do not receive such care.

In a study by Liptak and Revell,<sup>16</sup> respite care was rated as the most important service needed by parents of CSHCN. The lower proportion of families reporting re-

**Table 3. Unmet Respite Care Needs by CSHCN Characteristic**

Characteristic	Unmet Respite Care, %	P Value
Age, y		.67
12-17	26	
6-11	25	
<5	26	
Sex		.60
F	25	
M	23	
Residence		.05
Rural	19	
Urban	26	
Maternal education		<.001
≤High school	19	
>High school	29	
Insurance type		.04
Uninsured/gaps in insurance	33	
Public	22	
Private	24	
Other	20	
Household income, % of FPL		.09
>400	21	
200-399	30	
100-199	21	
<100	24	
Race/ethnicity		.86
Non-Hispanic white	23	
Non-Hispanic black	26	
Hispanic	26	
Other	25	
Functional limitations		<.001
None	8	
Some	20	
Severe	33	
Stability of condition		<.001
Usually stable	20	
Less stable	23	
Unstable	40	

Abbreviations: See Table 1.

spite care need in our study is probably because of the broad definition used to identify CSHCN in this study. The CSHCN Screener identifies children with mild conditions (eg, asthma, allergies) to very severe conditions (eg, mental retardation, autism).<sup>25</sup> Previous studies in which the sample included children with very complex health conditions showed a higher prevalence of respite care need than observed in this study.<sup>21</sup> Among children with disabilities receiving Supplemental Security Income (a more homogeneous population than ours), 25% reported need for respite care.<sup>21</sup>

Other reasons for low reported respite care need could be that parents may feel that seeking respite care is “giving up” on the child, or parents may lack awareness about respite care as a support service and hence not perceive a need for it.<sup>28</sup> Another possibility is the understanding of the term *respite care*. For example, in the most recent NSCSHCN (2006), caregivers were asked whether they needed respite care but not told what that meant.<sup>29</sup> This might have accounted for the lower proportion of respondents reporting respite care needs from the 2001 to 2006 surveys (9% vs 4%).<sup>30</sup> Future studies should evaluate

**Table 4. Adjusted Odds Ratios for Unmet Respite Care Needs<sup>a</sup>**

Characteristic	Odds Ratio (95% Confidence Interval)
Age, y	
12-17	1 [Reference]
6-11	1.0 (0.6-1.5)
<6	0.8 (0.5-1.4)
Sex	
F	1 [Reference]
M	1.0 (0.7-1.5)
Residence	
Rural	1 [Reference]
Urban	1.5 (1.0-2.3)
Maternal education	
≤High school	1 [Reference]
>High school	1.6 (1.1-2.31)
Household income, % of FPL	
>400	1 [Reference]
200-399	1.5 (0.9-2.7)
100-199	1.1 (0.6-2.1)
<100	1.4 (0.7-3.0)
Insurance type	
Uninsured/gaps	1 [Reference]
Public	0.47 (0.27-0.83)
Private	0.77 (0.43-1.38)
Other	0.40 (0.22-0.74)
Race/ethnicity	
Non-Hispanic white	1 [Reference]
Non-Hispanic black	1.4 (0.8-2.2)
Hispanic	1.2 (0.7-2.1)
Other	1.2 (0.5-2.9)
Functional limitations	
None	1 [Reference]
Some	2.5 (1.3-5.0)
Severe	5.6 (2.9-10.7)
Stability of condition	
Usually stable	1 [Reference]
Less stable	1.1 (0.7-1.6)
Unstable	2.3 (1.3-3.9)

Abbreviation: See Table 2.

<sup>a</sup>Adjusted in multivariate analysis for all other variables in the Table.

whether caregivers’ understanding of the term *respite care* varies by how the question is asked in surveys. A reliable and valid measure of respite care should be identified.

Parenting stress associated with caring for CSHCN decreases over time as caregivers are better able to cope with their child’s health condition.<sup>31</sup> This could account for our observation that caregivers of young CSHCN were more likely to report respite care need. Another possible explanation is that the child’s health condition could improve over time and make it more manageable for caregivers.

In our study, CSHCN with private insurance were less likely to need respite care. This observation probably reflects the overrepresentation of CSHCN with complex conditions in the public insurance group because of their eligibility for public insurance. Because of the cross-sectional nature of the NSCSHCN, it is not possible to evaluate whether greater respite care needs in CSHCN result in caregivers having to stop work and consequently becoming eligible for public insurance. The association between insurance status and need for respite care is complex and warrants further evaluation.

The CSHCN with functional limitations and unstable health conditions needed more respite care. The increased caregiving demands on the families of CSHCN with severe functional limitations could make these families report greater need for respite care. Prior studies show that families of children who have conditions with unpredictable courses, such as cystic fibrosis and sickle cell disease, often cause considerable psychological distress in families.<sup>10,12</sup> Our study provides further evidence that caring for CSHCN with unstable health conditions can cause substantial stress on the family.

The American Academy of Pediatrics recommends that support systems are in place for caring for CSHCN.<sup>14</sup> Yet, our study shows that the respite care needs of 1 of 4 families of CSHCN are not met. This translates to approximately 200 000 families with unmet respite care needs in the United States. This large unmet respite care need is concerning. With advances in technology, more and more children with complex and life-threatening conditions are surviving longer than in the past.<sup>32</sup> It is important to ensure adequate support systems for the family to care for their children for such prolonged periods.

The observation that maternal education was related to unmet respite care needs is intriguing and consistent with a previous report of unmet supportive services for children with disabilities.<sup>33</sup> It is possible that mothers with higher education are knowledgeable about the service systems and perceive services as unsatisfactory. Alternatively, mothers with poor education could have other family and social support systems unavailable to mothers with higher education.<sup>34,35</sup>

Our study shows that CSHCN with public insurance have far less unmet respite care need than those with private insurance and uninsured/had insurance gaps. This is probably because many private insurance plans are not comprehensive enough to provide support services such as respite care for CSHCN. In this time of intense debate about expanding public insurance for children, our study provides further evidence for the benefits of public insurance over private insurance in providing support services for CSHCN. Future studies should explore how state-level policies impact respite care provisions for CSHCN.

Our finding that CSHCN with severe functional limitations have the greatest unmet respite care needs is consistent with a previous report of very high unmet respite care needs (75%) among children with disabilities receiving Supplemental Security Income.<sup>21</sup> Needs of children with very complex conditions may be so high that there may not be adequate personnel to provide respite care, or their conditions make it difficult to access these services. The unpredictable nature of unstable health conditions may make it difficult for parents to find appropriate providers when necessary. It is important to evaluate the reasons for unmet respite care need for CSHCN with functional limitations and unstable health conditions.

In qualitative studies, parents report lack of availability of respite care providers as a barrier to access respite care.<sup>10</sup> While the nature of the NSCSHCN did not permit adequate exploration of the reasons, we found that at least one-fourth of those who had an unmet need re-

ported lack of availability or transportation problems as the reason for unmet respite care needs.

There are certain limitations to this study. First, the interpretation of what constitutes respite care need and whether the need is met can vary by characteristics of the respondents. There were differences in the proportion of CSHCN reporting need for respite care between the 2001 and 2006 NSCSHCN. The differences in how the respite care variable and some of the confounding variables were defined in the 2001 and 2006 NSCSHCN preclude us from making direct comparisons between the 2 surveys. Second, unmeasured confounding factors may be associated with respite care need and unmet respite care. For example, data on single-parent families, presence of other children in the family, and employment status of the caregivers are not available in this data set. Next, the data set lacks information on the type of respite care needed (location in home or out of home; duration and period of respite). There may be variation among communities in the availability of respite care resources, which cannot be determined from a national survey. Respite care need may vary by medical condition; this information is not available in the 2001 NSCSHCN. Future studies should evaluate respite care need and unmet respite care needs by medical condition; this information is available in the 2006 NSCSHCN. Finally, since this is a cross-sectional study, causality cannot be inferred in the associations that we observed between sociodemographic and health status factors and the respite care need and unmet respite care need.

## CONCLUSIONS

To our knowledge, this is the first study to describe information on respite care for CSHCN at a population level. Results from this study inform us about the subgroups of CSHCN who need respite care. This study has also identified disparities among CSHCN in access to respite care. This information will help to plan programs for CSHCN. Health care providers should ask families of CSHCN about their respite care needs and provide appropriate information on existing resources. Communities and states should identify existing support systems for CSHCN and their families and explore ways to improve these systems. Future population-based studies should determine whether The Life Span Respite Care Act of 2006 (passed by the US Congress in 2006 to assist family caregivers to access affordable respite care<sup>36</sup>) has decreased unmet respite care needs of CSHCN.

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**Correspondence:** Savithri Nageswaran, MD, MPH, Department of Pediatrics, Wake Forest University School of Medicine, Medical Center Boulevard, Winston-Salem, NC 27157 (snageswa@wfbmc.edu).

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## REFERENCES

1. McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998;102(1, pt 1):137-140.
2. McPherson M, Weissman G, Strickland BB, van Dyck PC, Blumberg SJ, Newacheck PW. Implementing community-based systems of services for children and youths with special health care needs: how well are we doing? *Pediatrics*. 2004; 113(5)(suppl):1538-1544.
3. Child and Adolescent Health Measurement Initiative. National Survey of Children's Health, Data Resource Center on Child and Adolescent Health Web site. www.nschdata.org. Accessed July 5, 2006.
4. Jessop DJ, Stein REK. Meeting the needs of individuals and families. In: Stein REK, ed. *Caring for Children With Chronic Illness: Issues and Strategies*. New York, NY: Springer Publishing Co; 1989.
5. Perrin JM, Shayne MW, Bloom SR. The impact on families. In: *Home and Community Care for Chronically Ill Children*. New York, NY: Oxford University Press; 1993:24-41.
6. van Dyck PC, Kogan MD, McPherson MG, Weissman GR, Newacheck PW. Prevalence and characteristics of children with special health care needs. *Arch Pediatr Adolesc Med*. 2004;158(9):884-890.
7. Stein REK. Challenges in long-term health care for children. *Ambul Pediatr*. 2001; 1(5):280-288.
8. Kuster PA, Badr LK. Mental health of mothers caring for ventilator-assisted children at home. *Issues Ment Health Nurs*. 2006;27(8):817-835.
9. Kirk S. Families' experiences of caring at home for a technology-dependent child: a review of the literature. *Child Care Health Dev*. 1998;24(2):101-114.
10. Nolan KJ, Camfield CS, Camfield PR. Coping with Dravet syndrome: parental experiences with a catastrophic epilepsy. *Dev Med Child Neurol*. 2006;48(9): 761-765.
11. Sari HY, Baser G, Turan JM. Experiences of mothers of children with Down syndrome. *Paediatr Nurs*. 2006;18(4):29-32.
12. Moskowitz JT, Butensky E, Harmatz P, et al. Caregiving time in sickle cell disease: psychological effects in maternal caregivers. *Pediatr Blood Cancer*. 2007;48 (1):64-71.
13. Montes G, Halterman JS. Psychological functioning and coping among mothers of children with autism: a population-based study. *Pediatrics*. 2007;119(5): e1040-e1046. <http://pediatrics.aappublications.org/cgi/content/full/119/5/e1040>.
14. Johnson CP, Kastner TA; American Academy of Pediatrics Committee/Section on Children With Disabilities. Helping families raise children with special health care needs at home. *Pediatrics*. 2005;115(2):507-511.
15. Perrin EC, Lewkowicz C, Young MH. Shared vision: concordance among fathers, mothers, and pediatricians about unmet needs of children with chronic health conditions. *Pediatrics*. 2000;105(1, pt 3):277-285.
16. Liptak GS, Revell GM. Community physician's role in case management of children with chronic illnesses. *Pediatrics*. 1989;84(3):465-471.
17. Botuck S, Winsberg BG. Effects of respite on mothers of school-age and adult children with severe disabilities. *Ment Retard*. 1991;29(1):43-47.
18. Sherman BR. Impact of home-based respite care on families of children with chronic illnesses. *Child Health Care*. 1995;24(1):33-45.
19. Cowen PS, Reed DA. Effects of respite care for children with developmental disabilities: evaluation of an intervention for at risk families. *Public Health Nurs*. 2002; 19(4):272-283.
20. Folden SL, Coffman S. Respite care for families of children with disabilities. *J Pediatr Health Care*. 1993;7(3):103-110.
21. Rupp K, Davies PS, Newcomb C, et al. A profile of children with disabilities receiving SSI: highlights from the National Survey of SSI Children and Families. *Soc Secur Bull*. 2005;66(2):21-48.
22. Blumberg SJ, Olson L, Frankel M, et al. Design and operation of the National Survey of Children with Special Health Care Needs, 2001. *Vital Health Stat 1*. 2003; (41):1-136.
23. National Survey of Children with Special Health Care Needs. <http://www.cdc.gov/nchs/about/major/slaits/nscshcn.htm>. Accessed November 22, 2004.
24. Bethell CD, Read D, Neff J, et al. Comparison of the children with special health care needs screener to the questionnaire for identifying children with chronic conditions—revised. *Ambul Pediatr*. 2002;2(1):49-57.
25. Bethell CD, Read D, Stein REK, Blumberg SJ, Wells N, Newacheck PW. Identifying children with special health care needs: development and evaluation of a short screening instrument. *Ambul Pediatr*. 2002;2(1):38-48.
26. Porterfield SL, McBride TD. The effect of poverty and caregiver education on perceived need and access to health services among children with special health care needs. *Am J Public Health*. 2007;97(2):323-329.
27. Mayer ML, Skinner AC, Slifkin RT; National Survey of Children With Special Health Care Needs. Unmet need for routine and specialty care: data from the National Survey of Children With Special Health Care Needs. *Pediatrics*. 2004;113(2): e109-e115. <http://pediatrics.aappublications.org/cgi/content/full/113/2/e109>. Accessed May 12, 2008.
28. Neufeld SM, Query B, Drummond JE. Respite care users who have children with chronic conditions: are they getting a break? *J Pediatr Nurs*. 2001;16(4):234-244.
29. 2005-06 National Survey of Children With Special Health Care Needs. Survey Instrument: English, page 52. <http://www.cdc.gov/nchs/data/slaits/NSCSHCNIIEnglishQuest.pdf>. Accessed May 12, 2008.
30. 2005-06 National Survey of Children With Special Health Care Needs. List of Variables: Interview PUF Variables, page 53. [http://www.cdc.gov/nchs/data/slaits/interview\\_formatted\\_freqs.pdf](http://www.cdc.gov/nchs/data/slaits/interview_formatted_freqs.pdf). Accessed May 12, 2008.
31. Singer LT, Salvator A, Guo S, Collin M, Lilien L, Baley J. Maternal psychological distress and parenting stress after the birth of a very low-birth-weight infant. *JAMA*. 1999;281(9):799-805.
32. Feudtner C, Hays RM, Haynes G, Geyer JR, Neff JM, Koepsell TD. Deaths attributed to pediatric complex chronic conditions: national trends and implications for supportive care services. *Pediatrics*. 2001;107(6):E99. <http://pediatrics.aappublications.org/cgi/content/full/107/6/e99>. Accessed May 12, 2008.
33. Benedict RE. Disparities in use of and unmet need for therapeutic and supportive services among school-age children with functional limitations: a comparison across settings. *Health Serv Res*. 2006;41(1):103-124.
34. Hoare P, Harris M, Jackson P, Kerley S. A community survey of children with severe intellectual disability and their families: psychological adjustment, carer distress and the effect of respite care. *J Intellect Disabil Res*. 1998;42(pt 3): 218-227.
35. Thurgate C. Respite for children with complex health needs: issues from the literature. *Paediatr Nurs*. 2005;17(3):14-18.
36. Skinner AC, Slifkin RT, Mayer ML. The effect of rural residence on dental unmet need for children with special health care needs. *J Rural Health*. 2006;22(1): 36-42.

Prevention is so much better than healing.  
—Thomas Adams, 1630