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Title Page  
Master of Public Health Research Project

Delayed and Forgone Care for Children with Special Health Care Needs  
in Virginia: A Cross-Sectional Study using 2005-2006 NS-CSHCN

by

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## **ABSTRACT**

### **Objectives**

The objectives of our study were to: 1) summarize illness characteristics and functional ability difficulties among Children With Special Health Care Needs (CSHCN) in Virginia, 2) examine the distribution of socio-demographic, health insurance, and health-related factors among Virginia's CSHCN, 3) quantify the influence of these socio-demographic, health insurance, and health-related factors on delayed and forgone care of CSHCN in Virginia, and 4) analyze reasons for delayed and forgone care among Virginia's CSHCN.

### **Methods**

Data from the 2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN) were used for this study. Three categories of predictor variables were studied: socio-demographic (age, gender, race/ethnicity, household income, parental education, family structure and residence area), health insurance (type of insurance, insurance continuity, insurance adequacy, and whether a child has usual source of health care), and illness variables (severity of condition, impact on functional abilities). Outcome variable was whether respondents reported having delayed or forgone health care for their children. We explored the relationship between predictor variables and outcome variable using bivariate and multivariable logistic regression analyses. All analyses were adjusted for the complex survey design using SAS 9.1.

### **Results**

Our data included 791 respondents, which represents 289,176 CSHCN from Virginia. Our results show that 6.1% of CSHCN in Virginia experienced delayed or forgone health care in the past 12 months. Bivariate analysis showed that lower income level, lower parental education, single parent household, lack of health insurance coverage, inadequate insurance, lack of continuous insurance coverage, lack of usual source of health care, severity of the condition, and impact on functional abilities were all significantly associated with delayed or forgone care. After adjusting for all potential confounders, multivariable analysis showed that family structure and insurance characteristics were significant predictors of delayed and forgone care. CSHCN who did not live in two-parent household (OR= 2.7; 1.05, 7.31), were ever uninsured during the past 12 months (OR = 17; 3.85, 75.58), had inadequate insurance (OR = 5.8; 2.06, 16.37), and who did not have a usual source of health care (OR = 22.6; 2.83, 180.55) had increased odds of delayed/forgone health care.

### **Conclusion**

Lapse in health insurance coverage, lack of usual source of health care, and insurance that is inadequate, all which are modifiable, are strong predictors of delaying or forgoing health care among CSHCN. It is important to identify families that are experiencing these barriers and to place special emphasis on children who do not stem from two-parent households. Policies and programs that address health insurance coverage and continuity, that increase the number of children with medical homes and usual sources of health care, and that address the needs of families that are particularly vulnerable should be implemented to guarantee CSHCN receive timely and needed health care.

## **INTRODUCTION**

### **Public health significance**

Children with special health care needs (CSHCN) are an exceptionally vulnerable population in our society. The Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau (MCHB) define CSHCN as children “...who have or are at increased risk for 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> This definition is used to develop family-centered, coordinated system of care for the CSHCN and their families who are served by the Maternal and Child Health Bureau’s Title V block grants. The definition includes children with a wide range of diagnoses who need various health care services, representing all racial and ethnic groups, ages, and family income. Children encompassed by the definition are children with various conditions, such as allergies, asthma, ADD/ADHD, depression, anxiety and emotional problems, migraines and frequent headaches, mental retardation, autism spectrum disorder, joint problems, seizure disorder, heart and blood problems, diabetes, cerebral palsy, down syndrome, muscular dystrophy, and cystic fibrosis.<sup>2</sup>

Children with special health care needs experience a variety of functional abilities, ranging from those who are rarely affected to those who are frequently and severely affected by their condition. Regardless of their condition, all CSHCN rely on medications or therapies, special education services, or assistive devices or equipment. CSHCN also require a wide range of medical and support services to care for their physical, mental, and emotional health, and development. Some of those services are prescription medications, specialty medical care, vision care, mental health care, specialized therapies, and medical equipment. Most of the

CSHCN do receive the services they need; however, according to the Maternal and Child Health Bureau, about 16 percent report at least one unmet need for services.<sup>3</sup>

### **Summary of literature**

Numerous studies suggest that raising a child with special health care needs and coping with the consequences of the child's conditions significantly affects family's economic stability.<sup>4-18</sup> The costs of caring for CSHCN are high relative to those for typically developing children; while CSHCN are estimated to make up 14% of the child population in the United States, they comprise 40% or more of medical spending for children overall.<sup>2</sup> Additionally, if a child greatly depends on a parent to provide or arrange care, the parent might reduce his or her work hours or stop working completely to meet the child's needs, further exacerbating the financial burden.<sup>6,7</sup> Studies found that financial or employment problems are more likely to occur among families with young children, with incomes below 200% federal poverty level, with children with severe conditions and children whose condition usually or always affected their functional abilities.<sup>8,9,10</sup> Financial problems are also more frequent among families who live in rural settings as compared to those who live in urban settings.<sup>11</sup> Lack of insurance and insurance continuity influence families' out of pocket costs and are directly related to family's financial burden.<sup>8,9,12-15</sup>

Multiple factors influence CSHCN's access to needed health care and support services and numerous studies have documented barriers to health care for children with special health care needs.<sup>19-33</sup> These barriers include socio-demographic factors, including but not limited to age, ethnicity, family income, parental education, and family structure. Some studies have shown that African American children, children of Hispanic ethnicity, children whose parents are not fluent in English language, those who live in rural areas, and children who live in low-

income families have been more likely to experience barriers to health care and unmet health care needs and services.<sup>19,22,26,27,29-33</sup> Others have documented that insurance type and status influence access to health care among children with special health care needs. Uninsured children, children who experience gaps in health insurance, and children who do not have a usual source of health care are less likely to obtain needed health care and services.<sup>19-23,25,26,32,33</sup> In addition, children with special health care needs who are severely affected by their illness are more likely to experience barriers to care.<sup>19,21,22,24,27,31-33</sup>

### **Research question**

In Virginia, it is estimated that 15.8% of children have special health care needs, which is slightly higher than the national average of 13.9%.<sup>34</sup> To date, no study analyzed Virginia CSHCN; thus, we hope to identify child and family characteristics associated with delayed and forgone care and to recognize groups of families that might benefit from additional resources and assistance. The objectives of the current study are to:

- summarize illness characteristics and functional ability difficulties among CSHCN in Virginia,
- examine the distribution of socio-demographic, health insurance, and health-related factors among Virginia's CSHCN,
- quantify the influence of these socio-demographic, health insurance, and health-related factors on delayed and forgone care of CSHNC in Virginia, and
- analyze reasons for delayed and forgone care among Virginia's CSHCN.

## **METHODS**

### **Data**

Data from the 2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN) were used for this study. This random-digit dial survey, which used the State and Local Area Integrated Telephone Survey platform, was conducted by the Centers for Disease Control and Prevention from April 2005 to February 2007, and was sponsored by the Maternal and Child Health Bureau (MCHB). The survey was designed to produce prevalence estimates of CSHCN, identify the type of services CSHCN need and use, and measure impact of having and taking care of a CSHCN on their families. The survey collected data at the state level and the survey design allows for calculation of state-level population estimates by applying the provided weights.

Trained interviewers asked parents or legal guardians of children less than 18 years of age in 191,640 households a series of questions to determine whether any of the children in the household had special health care needs. One CSHCN was randomly selected from each household to be the target of the detailed interview and a parent or guardian who was familiar with child's health was the respondent. A total of 40,273 special needs interviews were completed, including 791 for Virginia. Additional details about the survey methodology are described elsewhere.<sup>35</sup>

### **Description of Variables**

Three categories of predictor variables were studied: socio-demographic, health insurance, and illness variables. Socio-demographic variables we considered were: age, gender, race/ethnicity, household income, highest education level of parent or guardian, family structure and residence area. Race and ethnicity variables were merged and categorized as non-Hispanic



white, non-Hispanic black, and due to small sample size Hispanic and other were grouped into one category. Household income was calculated as percent of federal poverty level and grouped into three categories: less than 200%, 200% to 400% and more than or equal to 400% of federal poverty level. Highest education obtained by a parent or legal guardian was dichotomized as more than high school degree or high school degree or its equivalent and less than high school degree. Family structure was classified as either 1) two parent household, which included biological, adoptive, or step parents, and 2) single mother and other family structures. Residence area was dichotomized as either metropolitan area or non-metropolitan area.

Insurance characteristics were: type of insurance, insurance continuity, insurance adequacy, and whether a child has usual source of health care. Type of insurance was categorized as private, public or uninsured at the time of the survey. Respondents who answered that they had both private and public insurance and those who said they were insured but their type of insurance was unknown were classified as private. Insurance continuity was dichotomized as either insured all year or ever uninsured over the past 12 months. Insurance was categorized as either adequate or inadequate. We considered health insurance to be inadequate if health insurance benefits do not meet the needs of children, if the out-of-pocket costs are not reasonable, if insurance does not allow access to the provider the child needs, or if the child was uninsured.

Illness characteristics considered were severity of child's condition or problem and how severely and frequently were child's functional abilities affected. Severity of child's condition was classified as minor or moderate/severe. Effects on functional abilities were classified as 1) never affected, 2) sometimes, some, or very little affected, and 3) usually, always, or a great deal affected.

## **Delayed or Forgone Care of CSHCN**

The delayed or forgone care of CSHCN was determined using the following question from the detailed questionnaire: “During the past 12 months, have you delayed or gone without needed health care for the child?” If the answer to the question was positive, then the child was classified as having delayed or forgone care. It was explained to the respondents of the survey that health care means medical care as well as other types of care such as dental care, mental health services, physical, occupational, or speech therapies, and special education services. Therefore delayed and forgone care in this study includes these types of health care and services. Respondents who reported having delayed or forgone care for their children were then asked a series of reasons for delaying and forgoing care and whether any of these reasons pertain to them and their child.

## **Statistical analysis**

For our analysis we calculated distribution of all the predictor variables and prevalence of children with delayed and forgone care for each predictor variable. The strength of association between delayed/forgone care and characteristic variables was estimated using logistic regression modeling. Crude odds ratios and their 95% confidence intervals were calculated as preliminary measures of association. We used multivariable logistic model to provide estimates of odds ratios and their 95% confidence intervals for the association between predictor variables and delayed/forgone care after adjustment for all potential confounding factors. All analyses were adjusted for the complex survey design using SAS 9.1.

## **RESULTS**

### **CSHCN in Virginia**

Our data included 791 study samples, which represents 289,176 CSHCN from Virginia. Table 1 summarizes health conditions among CSHCN in Virginia. Top three conditions are allergies (59.4%), asthma (43.2%), and attention deficit disorder (32.1%). The conditions are not mutually exclusive, so a child might have one or more of the conditions.

Table 2 shows distribution of illness characteristics that need to be treated among CSHCN. Difficulty with breathing was the most common problem (46.4%), followed by difficulty with learning, understanding or paying attention (39.1%) and seeing without glasses (29.8%).

Table 3 shows the distribution of all the predictor variables. The majority of the children surveyed were above age 6 (81.7%), male (58.6%), non-Hispanic White (66.0%), lived in households with income level above 200% federal poverty level (64.6%), had a parent or guardian with more than high school diploma (71.4%), were from a two-parent household (65.3%), and lived in metropolitan areas (88.2%). Most children were covered by private health insurance (75.9%), were insured all year (92.5%), had adequate insurance (66.6%), and had a usual source of health care (96.4%). Severity of the condition was minor for about half of the children (50.9%) and moderate or severe for the other half (49.1%), and most children's functional abilities were either never affected or were sometimes, some or very little affected by their condition (77.9%).

### **Delayed/Forgone Care**

Our results show that approximately 6.1% of CSHCN in Virginia had the experience of delaying or forgoing health care in the past 12 months. Table 4 shows the estimated proportions

of delayed and forgone care by socio-demographic, health insurance, and health-related predictor variables among the children.

Table 5 shows the results from the logistic regression model examining predictor variables. Bivariate analysis showed that lower income level, lower parental education, single parent household, lack of health insurance coverage, inadequate insurance, lack of continuous insurance coverage, lack of usual source of health care, severity of the condition, and impact on functional abilities were all significantly associated with delayed or forgone care. After adjusting for all potential confounders, multivariable analysis showed that family structure and insurance characteristics were significant predictors of delayed and forgone care. CSHCN who did not live in two-parent household were about 2.7 times (95% CI [1.05, 7.31]) more likely to experience delaying or forgoing of health care compared to children who live in two-parent household. CSHCN who were ever uninsured during the past 12 months were about 17 times (95% CI [3.85, 75.58]) more likely to have their care delayed or forgone compared to children who were continuously insured over the past year. CSHCN who had inadequate insurance were about 5.8 times (95% CI [2.06, 16.37]) more likely to experience delayed or forgone care, compared to children with adequate insurance. CSHCN who did not have a usual source of health care were 22.6 times (95% CI [2.83, 180.55]) more likely to experience delayed/forgone health care, compared to children with usual source of health care.

Table 6 shows reasons for delayed/forgone care. Approximately 67% of parents cited that they did not have money to pay the provider, 41% said the type of care needed was not covered by the health plan, and 33% said the appointment conflicted with other home or work responsibilities.

## DISCUSSION

Among Virginia's CSHCN 6.1% experienced delayed or forgone care. While this statistic is small, it represents approximately 17,571 children in Virginia who did not receive the care they might have needed. Studying factors that influence delayed/forgone care is valuable as it helps us identify characteristics of families that might benefit from additional resources. Allergy (59%), asthma (43%), and attention deficit disorder (32%) were the most common conditions among Virginia's CSHCN. Although proportion of Virginia's CSHCN who experience these conditions is higher than the national average, our findings are consistent with the national data which shows that allergies (53%), asthma (39%), and attention deficit disorder (30%) comprise the top three conditions among CSHCN nationally.<sup>36</sup> The leading limitations experienced by CSHCN in Virginia were difficulty with breathing (46%), learning, understanding, or paying attention (39%), and seeing without glasses (30%).

Similar to other studies<sup>19-23,25,26,32,33</sup>, we found that insurance characteristics were associated with delayed and forgone care among Virginia's CSHCN. While type of insurance (private or public) does not appear to influence failure to obtain care, lapse in insurance coverage, inadequate insurance, and lack of usual source of health care all seem to influence whether a child will experience delayed or forgone health care. 37% of CSHCN who were uninsured at some point during the year experienced delayed or forgone health care, and had 17 times higher odds of delayed or forgone care than children who were continuously insured. Similarly, 22% of children without a usual source of health care experienced delayed/forgone care and were 23 times more likely to either delay or forgo health care that was needed compared to children with usual source of health care. Of the children with inadequate insurance, 13% experienced delayed or forgone care, and these children had 6 times higher odds to delay/forgo

needed care compared to children with adequate health insurance. Given the high prevalence of delayed/forgone care among these children and the large odds ratios associated with these health insurance characteristics, an examination of factors that contribute to these health insurance factors is strongly warranted. Interestingly, our adjusted model shows that uninsured status was not significantly related to delayed and forgone health care. 40% of CSHNC who were uninsured at the time of the survey experienced delayed/forgone care and the crude odds ratios showed a large association between lack of insurance and delayed/forgone health care. This association, however, was accounted for by insurance continuity variable in the adjusted model. Additionally, we suspect that this result could partially be explained by the small number of uninsured children in our sample. These findings were consistent with principal reasons reported by respondents for not obtaining needed health care: provider costs and problems with health plan.

Our crude analysis showed an association between some of the socio-demographic factors and delayed/forgone care. Income level, parental education, and family structure were shown to be indicators of delayed/forgone care. After adjusting for potential confounders, however, with the exception of family structure, these relationships were shown to be insignificant and were accounted for by health insurance characteristics. Respondents who classified their households as either single mother or other than two parent households showed a strong association with delayed/forgone care. Specifically, CSHCN who live in such households had 2.8 the odds of their care being delayed or forgone compared to children who live in two parent families. This finding is not surprising considering that families without two parents face significant disadvantages over two parent households.<sup>37</sup> Children's utilization of health care is made easier by having two parents to fulfill various roles, such as learning about suggested

health care for their children, taking children to various appointments, picking up medications from the pharmacy, and returning for follow-up care. Completing all these duties might be difficult for single parents and parents in non-traditional households. Due to sample size limitations, we were unable to assess the impact of language spoken at home on health care impediment. Similarly to our study, Smaldone et al.<sup>20</sup> analyzed delayed and forgone care and its determinants among CSHCN in New York state using 2000-2001 NS-CSHCN, and found no association between socio-demographic factors and delayed/forgone care. Our findings are somewhat inconsistent with other studies that reported significant relationship between other socio-demographic factors and failure to obtain health care.<sup>19,22,26,27,29-33</sup> The reason for this inconsistency is most likely due to methodological differences. These studies analyzed unmet needs for different types of care separately, such as routine, specialty, dental, and mental health care and/or had a much larger sample size as they used nationally representative data. Kane et al.<sup>19</sup>, for example, analyzed the determinants associated with unmet need for routine and specialty care in Mississippi using 2000-2001 NS-CSHCN. In their adjusted model they found a significant relationship between lower income level and unmet specialty care but no association between socio-demographic determinants and unmet routine preventive care.

Our crude analysis showed a significant association between severity of child's condition and impediment on child's functional abilities by their condition and child's delayed/forgone care. After adjusting for potential confounders, however, these associations were shown not to be significant and were accounted for by health insurance characteristics. Our findings here also slightly differ from previous research<sup>19,21,22,24,27,31-33</sup>. Our study is different from these studies in that it analyzed a different outcome variable and is therefore not completely comparable to some of the studies. While we analyzed delayed/forgone care which encompassed various types of

health care, many of these studies only looked at one type of health care, such as routine, specialty, or dental care, or various types of care separately.<sup>19,22,24</sup> We also used data for one state therefore limiting our sample size, whereas a large number of studies that found an association between utilization of health care and child's illness characteristics used national data and thus had a much larger sample.<sup>27,31,33</sup> Strickland et al.<sup>27</sup>, for example, found that impact on functional abilities due to child's condition significantly influenced child's delayed/forgone care using national data from the 2000-2001 NS-CSHCN.

One of the restrictions of our findings is that our output variable, delayed and forgone care, does not distinguish among different types of care: routine preventive care, specialty care, mental health services, dental care, etc. While the NS-CSHCN does ask about each of these types of care and whether it was needed and received, we were unable to analyze these different types of care individually due to the small sample size of the Virginia sample. We did, however, include a table in the Appendix that shows the number and percent of CSHCN who needed each type of care and the number and percent of children who needed this care but did not obtain it.

A limitation of this study was that data was obtained via a telephone survey; therefore, people without phones or those who solely rely on cell phones were excluded from the study. Additionally, all data was self reported and assumed to contain some information bias. Parents and guardians reported whether their child needed health care and child's illness characteristics. While their perception of child's health care needs and illness severity are important measures, they may be biased measures and may not reflect actual need for care or illness severity. Another limitation of the study was the small sample size which contributed to wide confidence intervals in the logistic regression analysis and lowered the power of the statistical methods. The findings of our study, therefore, should be interpreted with caution.



The findings of our study offer useful information to health care providers and public health professionals in Virginia. Lapse in health insurance coverage, lack of usual source of health care, and insurance that is inadequate, all which are modifiable, are strong predictors of delaying or forgoing health care among CSHCN. It is important, therefore, to identify families that are experiencing these barriers and to place special emphasis on children who do not stem from two-parent households. To ensure CSHCN receive timely health care, children should have a regular source of health care, a personal doctor or nurse, experience no difficulty in obtaining referrals for specialty care, receive needed care coordination and health care that is family-centered.<sup>38</sup> In addition to regular and coordinated health care, children should be covered by adequate health insurance with benefits that meet the needs of the child, allow access to the provider the child needs, and encompass reasonable out-of-pocket costs. CSHCN who are covered by health insurance need to remain insured, since those children who experience lapse in insurance coverage are more likely to experience delayed or forgone care. Policies and programs that address health insurance coverage and continuity, that increase the number of children with medical homes and usual sources of health care, and that address the needs of families that are particularly vulnerable should be implemented to guarantee CSHCN receive timely and needed health care.

## TABLES

**Table 1. Distribution of illnesses among CSHCN: Virginia 2005-2006**

Child has	N <sup>*</sup>	Weighted N <sup>#</sup>	Weighted % <sup>^</sup>
Allergies	451	171,872	59.4
Asthma	303	125,012	43.2
Attention Deficit Disorder	250	92,593	32.1
Emotional problems	125	47,860	16.6
Migraine or frequent headaches	113	45,997	15.9
Mental retardation	97	38,388	13.3
Autism	45	15,258	5.3
Heart problems	30	11,552	4.0
Seizure disorder	32	10,862	3.8
Joint problems	27	8,948	3.1
Blood problems	15	6,925	2.4
Cerebral Palsy	17	6,473	2.2
Diabetes	13	5,775	2.0
Down Syndrome	11	3,421	1.2
Muscular Dystrophy	2	669	0.2
Cystic Fibrosis	1	277	0.1

\* unweighted N, number of surveyed respondents

# number of the population that the respondents represent

^ proportion of the population that the respondents represent

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs 2005-2006

**Table 2. Distribution of illness characteristics and functional abilities among CSHCN: Virginia 2005-2006**

Child has difficulty with	N <sup>*</sup>	Weighted N <sup>#</sup>	Weighted % <sup>^</sup>
Breathing	333	134,083	46.4
Learning, understanding, or paying attention	305	111,602	39.1
Seeing without glasses	235	86,082	29.8
Feeling anxious or depressed	182	70,024	25.1
Behavior problems	173	67,902	24.4
Making and keeping friends	138	53,827	19.9
Speaking, communicating, or being understood	147	56,095	19.7
Repeated or chronic physical pain	125	49,521	17.1
Coordination	117	41,288	14.3
Using hands	94	33,941	11.7
Taking care of self	79	29,869	11.1
Swallowing, digesting food, or metabolism	71	29,019	10.0
Hearing without a hearing aid	31	10,809	3.7
Blood circulation	21	7,093	2.5

\* unweighted N, number of surveyed respondents

# number of the population that the respondents represent

^ proportion of the population that the respondents represent

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs 2005-2006

**Table 3. CSHCN Population Estimates: Virginia 2005-2006**

Characteristics/variable	N*	Weighted N#	Weighted % <sup>^</sup>
<b>Socio-demographic variables</b>			
Age (years)			
0 - 5	128	52,809	18.3
6 - 11	328	119,696	41.4
12 - 17	335	116,671	40.4
Gender			
Female	318	119,555	41.4
Male	472	169,172	58.6
Race/ethnicity			
White, non-Hispanic	584	188,237	66.0
Black, non-Hispanic	119	70,147	24.6
Hispanic & Other	77	26,774	9.4
Income as % of poverty level			
>= 400	321	92,904	35.3
200 < 400	222	76,986	29.3
< 200	172	93,280	35.4
Highest education level			
> High school diploma	663	206,358	71.4
High school graduate or less	128	82,818	28.6
Family structure			
2 parent (biological or adoptive or step)	541	181,147	65.3
Single mother & Other	221	96,260	34.7
Residence			
Metropolitan area	706	255,171	88.2
Non-Metropolitan area	85	34,005	11.8
<b>Insurance characteristics</b>			
Type of insurance			
Private	652	218,843	75.9
Public	123	63,843	22.1
Uninsured	14	5,722	2.0
Insurance continuity			
Insured all year	745	266,632	92.5
Ever uninsured over past 12 months	44	21,776	7.6
Insurance adequacy			
Adequate insurance	524	189,995	66.6
Inadequate insurance	244	89,574	33.4

Has usual health care source			
Yes	767	278,467	96.4
No	23	10,315	3.6

**Illness characteristics**

Severity of child's condition/problem			
Minor	362	123,494	50.9
Moderate/Severe	291	118,959	49.1

Functional abilities: how severely and frequently affected

Never affected	316	108,770	37.6
Sometimes, some, very little	304	116,472	40.3
Usually, always, a great deal	171	63,934	22.1

\* unweighted N, number of surveyed respondents

# number of the population that the respondents represent

^ proportion of the population that the respondents represent

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs 2005-2006

**Table 4. Estimated proportion of delayed/forgone care for CSHCN: Virginia 2005-2006**

Characteristics/variables	Delayed/forgone care N=43 <sup>*</sup> Weighed N=17,571 <sup>#</sup>			Care not delayed/forgone N=747 <sup>*</sup> Weighted N=271,418 <sup>#</sup>		
	% <sup>^</sup>	95% CI		% <sup>^</sup>	95%CI	
<b>Socio-demographic variables</b>						
Age (years)						
0 - 5	16.7	0.4	33.0	18.4	15.0	21.7
6 - 11	35.7	19.6	51.8	41.8	37.6	46.0
12 - 17	47.6	30.1	65.1	39.8	35.8	43.9
Gender						
Female	42.6	25.5	59.7	41.4	37.2	45.5
Male	57.4	40.3	74.5	58.6	54.5	62.8
Race/ethnicity						
White, non-Hispanic	54.0	36.1	72.0	66.8	62.5	71.2
Black, non-Hispanic	35.3	16.5	54.1	23.9	19.7	28.1
Hispanic & Other	10.7	1.5	19.9	9.2	6.8	11.7
Income as % of poverty level						
>= 400	13.1	2.4	23.7	36.7	32.7	40.7
200 < 400	26.9	10.8	42.9	29.4	25.6	33.3
< 200	60.1	42.3	77.9	33.9	29.2	38.5
Highest education level						
> High school diploma	50.4	32.7	68.0	72.7	68.3	77.1
High school graduate or less	49.6	32.0	67.3	27.3	22.9	31.7
Family structure						
2 parent (biological or adoptive or step)	37.5	21.5	53.6	67.1	62.9	71.4
Single mother & Other	62.5	46.4	78.5	32.9	28.6	37.1
Residence						
Metropolitan area	83.8	67.5	100.0	88.5	85.7	91.3
Non-Metropolitan area	16.2	0.0	32.5	11.5	8.7	14.3
<b>Insurance characteristics</b>						
Type of insurance						
Private	53.3	35.1	71.5	77.3	73.4	81.2
Public	33.2	14.8	51.7	21.4	17.6	25.3
Uninsured	13.4	0.4	26.5	1.3	0.3	2.2
Insurance continuity						
Insured all year	52.6	34.5	70.7	95.0	92.9	97.0

Ever uninsured over past 12 months	47.4	29.3	65.5	5.0	3.0	7.1
Insurance adequacy						
Adequate insurance	27.7	13.0	42.3	69.1	65.2	72.9
Inadequate insurance	72.3	57.7	87.0	30.9	27.1	34.8
Has usual health care source						
Yes	86.6	76.0	97.3	97.1	95.4	98.7
No	13.4	2.7	24.0	2.9	1.3	4.6
<b>Illness characteristics</b>						
Severity of child's condition / problem						
Minor	31.0	14.8	47.3	52.4	47.7	57.1
Moderate/Severe	69.0	52.7	85.2	47.6	42.9	52.3
Functional abilities: how severely and frequently affected						
Never affected	13.6	1.9	25.3	39.2	35.1	43.3
Sometimes, some, very little	41.2	24.3	58.2	40.2	36.1	44.4
Usually, always, a great deal	45.2	27.5	62.9	20.6	17.1	24.0

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\* unweighted N, number of surveyed respondents

# number of the population that the respondents represent

^ proportion of the population that the respondents represent

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs 2005-2006

**Table 5. Crude and adjusted analysis examining delayed/forgone care among CSHCN: Virginia 2005-2006**

Characteristics/variables	Delayed/Forgone Care Prevalence	Crude			Adjusted		
		OR	95% CI	OR	95% CI		
<b>Socio-demographic variables</b>							
Age (years)							
0 - 5	5.6	1.00			1.00		
6 - 11	5.2	0.94	0.27	3.31	1.22	0.32	4.67
12 - 17	7.2	1.31	0.38	4.54	1.68	0.38	7.47
Gender							
Female	6.1	1.00			1.00		
Male	5.8	0.95	0.46	1.96	0.99	0.39	2.51
Race/ethnicity							
White, non-Hispanic	5.0	1.00			1.00		
Black, non-Hispanic	8.8	1.83	0.76	4.36	0.46	0.15	1.43
Hispanic & Other	7.1	1.43	0.52	3.95	1.25	0.23	6.81
Income as % of poverty level							
>= 400	2.3	1.00			1.00		
200 < 400	5.6	2.56	0.85	7.74	2.82	0.55	14.41
< 200	10.4	<b>4.98</b>	<b>1.81</b>	<b>13.74</b>	2.55	0.43	15.02
Highest education level							
> High school diploma	4.3	1.00			1.00		
High school graduate or less	10.5	<b>2.62</b>	<b>1.25</b>	<b>5.50</b>	2.05	0.77	5.44
Family structure							
2 parent (biological or adoptive or step)	3.6	1.00			1.00		
Single mother & Other	11.2	<b>3.40</b>	<b>1.67</b>	<b>6.92</b>	<b>2.77</b>	<b>1.05</b>	<b>7.31</b>
Residence							
Metropolitan area	5.8	1.00			1.00		
Non-Metropolitan area	8.4	1.50	0.44	5.09	0.70	0.17	2.86
<b>Insurance characteristics</b>							
Type of insurance							
Private	4.2	1.00			1.00		
Public	9.0	2.25	0.94	5.38	1.10	0.34	3.53
Uninsured	40.4	<b>15.46</b>	<b>3.92</b>	<b>60.94</b>	0.31	0.05	2.03
Insurance continuity							
Insured all year	3.4	1.00			1.00		



Ever uninsured over past 12 months	37.4	<b>17.01</b>	<b>7.31</b>	<b>39.59</b>	<b>17.06</b>	<b>3.85</b>	<b>75.58</b>
Insurance adequacy							
Adequate insurance	2.5	1.00			1.00		
Inadequate insurance	13.1	<b>5.84</b>	<b>2.74</b>	<b>12.42</b>	<b>5.81</b>	<b>2.06</b>	<b>16.37</b>
Has usual health care source							
Yes	5.5	1.00			1.00		
No	22.8	<b>5.09</b>	<b>1.73</b>	<b>15.02</b>	<b>22.59</b>	<b>2.83</b>	<b>180.55</b>
<b>Illness characteristics</b>							
Severity of child's condition / problem							
Minor	4.1	1.00			1.00		
Moderate/Severe	9.6	<b>2.45</b>	<b>1.12</b>	<b>5.35</b>	0.63	0.16	2.49
Functional abilities: how severely and frequently affected							
Never affected	2.2	1.00			1.00		
Sometimes, some, very little	6.2	<b>2.95</b>	<b>1.02</b>	<b>8.57</b>	2.05	0.32	12.99
Usually, always, a great deal	12.5	<b>6.33</b>	<b>2.11</b>	<b>19.04</b>	6.75	0.63	71.89

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Note: OR: Odds ratio; CI: Confidence interval; All variables were included in the multivariable model  
Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs 2005-2006

**Table 6. Reasons for delayed and forgone care for CSHCN: Virginia 2005-2006**

Reasons for delayed/forgone care	N <sup>*</sup>	Weighted N <sup>#</sup>	Weighted % <sup>^</sup>
Did not have money to pay provider	27	11,681	66.5
Type of care not covered by health plan	18	7,228	41.1
Appts conflict with other home or work responsibilities	13	5,824	33.1
Could not get approval from health plan or doctor	10	3,737	21.3
Clinic/office not open when I could go	12	3,437	19.6
Could not get appt soon enough	10	3,347	19.0
Could not reach provider office by telephone	6	3,313	18.9
Type of care needed not provided in area	8	2,748	15.6
Transportation was a problem	5	2,042	11.6
Provider did not have skills child needed	6	1,968	11.2
Child has to wait too long to see provider in office	4	1,728	9.8
Language, communication, cultural problems with provider	0	0	0.0

\* unweighted N, number of surveyed respondents

# number of the population that the respondents represent

^ proportion of the population that the respondents represent

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs 2005-2006

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**APPENDIX**

### Unmet need for care by type of care among CSHCN: Virginia 2005-2006

Type of care	Reported need for care			Of those who reported need for care, did not receive needed care		
	N*	Weighted N <sup>#</sup>	Weighted % <sup>^</sup>	N*	Weighted N <sup>#</sup>	Weighted % <sup>^</sup>
Routine preventive	644	227,674	78.7	11	3,453	1.5
Specialty	449	159,013	55.0	20	6,688	4.2
Preventive dental	669	236,508	81.8	30	12,377	5.2
Other dental	215	71,249	24.6	10	3,964	5.6
Prescriptions	704	253,940	6736.0	11	3,990	1.6
Phys/occup/speech therapy	189	70,821	24.5	21	7,291	10.3
Mental health	164	60,419	20.9	23	8,902	14.7
Substance abuse treatment	9	4,238	2.1	1	374	8.8
Home health	24	9,869	3.4	2	554	5.6
Eyeglasses/vision	262	93,362	32.3	7	2,494	2.7
Hearing aids and hearing care	35	12,720	4.4	2	877	6.9
Mobility aids or devices	37	14,408	5.3	3	990	6.9
Communication aids and devices	13	3,845	1.4	2	1,112	28.9
Medical supplies	142	53,560	18.5	4	2,878	5.4
Durable medical equipment	89	33,807	11.7	2	1,825	5.4
Respite care	27	10,286	3.6	19	7,473	72.7
Genetic counseling	36	14,311	5.0	8	2,981	20.8
Family mental care	87	34,160	11.8	21	9,632	28.2

\* unweighted N, number of surveyed respondents

# number of the population that the respondents represent

<sup>^</sup> proportion of the population that the respondents represent

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs 2005-2006