Health Status and Access to Care for Children with Special Health Care Needs

Darrell J. Gaskin,^{1*} Jean M. Mitchell²

¹Ph.D., Associate Professor, Department of Health Policy and Management Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA ²Ph.D., Professor, Georgetown Public Policy Institute, Washington, D.C., USA

Abstract

Background: About 11-14% of children with special health care needs (CSHCN) have unmet needs during a given year. Little is known about the determinants of unmet health care needs for CSHCN.

Aims of the Study: The objective of this study was to explore the association between access to care (unmet needs) among CSHCN and their caregivers' mental health status as well as children's mental health status.

Methods: We surveyed a random sample of 1,088 caregivers of CSHCN who resided in the District of Columbia during the summer and fall of 2002. In the survey, we collected information on children's unmet needs mental health status (PARS) and their caregivers' mental health status (CES-D). We estimated the association between mental health status determinants of unmet needs adjusting for selection bias associated with plan choice (partially capitated managed care versus FFS) with an instrumental variables probit estimation technique. We used caregivers' preferences about physicians and hospitals networks, and whether the caregiver and child had the same last name to identify the plan choice equation.

Results: We found that caregivers with symptoms of depression were 26.3% more likely to report any unmet need, 67.6% more likely to report unmet hospital and physician need, 66.1% more likely to report unmet mental health care need and 38.8% more likely to report unmet need for other health care services. Caregivers of children with poor psychological adjustment were 26.3% more likely to report their child had an unmet need and 92.3% more likely to report an unmet mental health care need.

Discussion: Our analyses show that children whose caregivers experience symptoms of depression are significantly more likely to encounter difficulties obtaining needed medical and mental health care services. Furthermore, the findings reported here indicate that children with poor psychological adjustment are significantly more likely to experience unmet needs for medical and mental health care services. Our study has some limitations. First, most of the children in our sample are African-American, so these findings may differ for children of other races. Second, these findings may not be applicable to CSHCN who reside in rural areas. Third, we recognize the possibility that child and caregiver mental health is potentially endogenous.

Implications for Health Care Provision and Use: The mental health status of CSHCN and their caregivers are barriers to care.

Implications for Health Policies: Policymakers should be concerned about the mental health status of children with special health care needs and their caregivers as such problems appear to be barriers to obtaining care. Therefore, to adequately address the access problems of children with special health care needs, policy must address the mental health problems of children and their caregivers. Providing mental health care for caregivers and children has the potential for improving overall access for CSHCN.

Implication for Further Research: Future research should determine the causal relationship between mental health problems of CSHCN and their caregivers and the level unmet health care needs.

Received 20 September 2004; accepted 3 March 2005

Introduction

National estimates of the percent of US children with special health care needs (CSHCN) range from 12 to 20%.¹⁻³ The Maternal and Child Health Bureau (MCHB) defines children with special health care needs as "those who have or are at increased risk of 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."^{1,4} CSHCN were more likely to have health insurance coverage and a usual source of care than other children. However, despite slightly better access they are more likely to have unmet health care needs. Using data from the National Health Interview Survey, researchers have estimated between 11.3 and 13.8 percent of CSHCN have unmet health care needs.^{2,3,5} Unmet needs were most often reported for dental care, prescription drugs and vision care. Estimates for unmet mental health needs increased for 1.2% in 1994 to 3.3% in 2001. Using data from National Survey of Children with Special Health Care Needs conducted during 2000-2002, Mayer et al.⁶ report that 3.2% of CSHCN were unable to obtain routine preventive care and 7.2% were unable to obtain specialty care.

Little is known about the determinants of unmet health care needs for CSHCN. Mayer *et al.* using logistic regression analysis identified factors associated with unmet needs for

^{*} **Correspondence to:** Darrell J. Gaskin, Ph.D., Associate Professor, Center for Health Disparities Solutions, Department of Health Policy and Management, Johns Hopkins Bloomberg, School of Public Health, 624 North Broadway, Room 441, Baltimore, MD 21205, USA.

Tel.: +1-443-287 5297

Fax: +1-410-614 8964

E-mail: dgaskin@jhsph.edu

Source of Funding: This research was supported by grant R01 HS 10912 from the Agency for Healthcare Research and Quality and the National Institute of Child Health and Human Development.

routine and specialty care.⁶ They found that among CSHCN, African American children, children whose mothers had less than a high school education, poor and near poor children and uninsured children were more likely to have an unmet need for routine care. Further, they reported that older children, as well as those who were poor, near poor or uninsured were more likely to have an unmet need for specialty services. Using data from the 1994 and 1995 NHIS, Newacheck *et al.* report uninsured children were 3.2 to 5.8 times more likely to have an unmet health care needs depending on the type of need and controlling for predisposing, enabling and need factors.³

Given the sparse literature on unmet needs from CSHCN, additional research is needed to obtain a greater understanding about how their families cope with their constant health care needs. This study takes advantage of 2002 Survey of Caregivers of CSHCN in the District of Columbia who were enrolled in the DC Medicaid program.⁷ Since 1996, the District of Columbia's Medicaid Program have offered parents of CSHSN the opportunity to enroll their children in a managed care plan, Health Services for Children with Special Needs, Inc. (HSCSN). HSCSN is a partially capitated HMO that provides a comprehensive array of services for enrolled children including primary and specialty medical care, mental health, and an array of ancillary and support services. HSCSN contracts with a wide array of providers to deliver services to enrolled children. Under HSCSN, primary care physicians, specialists and dentists are reimbursed at rates that are approximately twice the amounts paid by Medicaid FFS. In contrast, HSCSN and Medicaid FFS pay similar and sometimes identical rates for home health care, therapy services and durable medical equipment and supplies. To coordinate services, each child enrolled in HSCSN is assigned a primary care physician (PCP) and case manager. See Mitchell and Gaskin for a more detailed description of this study, the DC Medicaid program and HSCSN.

The 2002 Caregiver's survey was fielded to evaluate the impact of HSCSN versus the FFS option on access to care for CSHCN in the DC Medicaid program. Mitchell and Gaskin found that enrollment in the partially capitated managed care plan was associated with a lower prevalence of unmet needs and improved access to care measured along several dimensions. In that analysis, we controlled for other factors including the mental health status of children and their primary caregiver. Previous analyses focused solely on the impact of managed care on unmet needs and other access to care measures. This article focuses on the findings related to the mental health status of children and their primary caregiver. Specifically, our objective is to evaluate whether either the mental health status of the special needs child and/ or their primary caregiver are associated with having unmet need for medical care, mental health services and dental care.

Our conceptual framework for this analysis is a modified version of Andersen and Aday's behavioral health model of access to care.⁸⁻¹⁰ Access to care is determined by predisposing factors (demographic, social structure and parental attitudes and beliefs), enabling factors (family resources and health care resources in the community) and 30

children's health care needs. We anticipate that children with poor mental health will experience greater access problems than those with good mental health. Further, we hypothesize that children of caregivers with depressive symptoms will encounter greater access problems than those in better mental health.

Models of help-seeking behavior emphasize the importance of recognizing children's health needs and children's interactions with their parents and providers and organizations that can facilitate health services use.¹¹⁻¹⁶ Poor mental health status may negatively affect caregivers' and other responsible adults' ability to assess their child's health need. Poor mental health status may impair children's ability to effectively communicate their health care needs to their caregivers and adults. Also, behavioral problems associated with children's poor mental health status may discourage parents from seeking care because their children may be perceived by providers as difficult patients. Caregivers' mental health status may affect their ability to recognize their children's health needs. Poor mental status may impair caregivers' judgment about the nature and severity of their children's symptoms. In addition, depressed caregivers may be less incline to overcome other barriers to care, e.g., transportation or child care problems.

Methods

Because caregivers are given the option of enrolling their children in regular Medicaid fee-for-service or a partially capitated managed care plan (HSCSN), we must control for possible selection bias linked to plan choice. We model plan choice, that is, the decision to enroll in HSCSN or remain in FFS as a function of children's physical, cognitive and emotional health status, family structure, their caregivers' mental health status, household economic status, caregivers' preferences regarding health care provider, and the ability of the managed care plan to the contact caregivers to provide them with information about the MC plan.

Data and Variable Definitions

The data for the analysis come from a 2002 telephone survey of 1,088 caregivers of CSHCN enrolled in the DC Medicaid program. The caregiver was identified as the person in the household who arranged most of the health care for the child. The telephone survey was fielded by CODA, Inc., a professional survey research firm located in Silver Spring. MD. The overall response rate for the study was 46%, excluding non-locatable cases from the denominator yields an overall cooperation rate of 81%. See Mitchell and Gaskin for more details.⁷

The dependent variables of interest are six indicators of unmet health care need. Caregivers were asked a series of questions to determine if their child had an unmet need. First, they were asked if their child in the last six months had a need for a particular service. If they responded "yes", then they were asked as a follow-up question, "did the child receive the service?" If they responded "no", we asked them for reasons why the child did not receive the service. We asked this series of questions for health services ranging from hospital care to home health services. From the caregivers' responses we created six indicators of unmet need.

The first is a general indicator of unmet need which indicate the caregiver reported that the child had an unmet need for one or more of the following services: emergency room, overnight hospital stay; shot, immunization or checkup; visit with a primary care physician or physician's assistant; visit with a medical specialist; visit with a mental health specialist; visit with a physical, occupational or speech therapist; dental care; prescribed medications; medical equipment or supplies; and home health services.

The second indicator identifies those children who had an unmet need for a shot, immunization or checkup.

The third indicator identifies those children who had an unmet emergency room visit, hospital stay, physician visit for a minor illness or specialty visit.

The fourth indicator identifies those children who had an unmet need for mental health care needs.

The fifth indicator distinguishes those children who had an unmet need for dental care.

The final indicator includes all other unmet needs such as home health services, prescribed medicine, medical equipment or supplies, and physical, occupational or speech therapy.

The independent variables of primary interest include measures of children's and their caregivers' mental health status. We used the PARS to measure the child's psychosocial adjustment.¹⁷ The PARS is a parent-reported measure of the disabled child's psycho-social functioning across six specific dimensions: peer relations, dependency, hostility, productivity, anxiety/depression and withdrawal. Caregivers responded with a four-point scale (ordered from "always" to "never (rarely)" to 28 items that begin with the statement "In the past 30 days has (CHILD) "..." Higher scores on the PARS reflect better psychological adjustment. To measure the caregiver's mental health we used a 7-item version of the Center for Epidemiological Studies -Depression scale (CES-D).^{18,19} The 7-item scale focuses on dysphoria, sleep, concentration, fatigue and loneliness. Higher scores indicate that a caregiver is suffering with depression symptoms.

Data Analytic Procedures

We conducted bivariate and multivariate analyses. For the bivariate analyses we divided the children into two groups: those with poor psychological adjustment (PARS score < 66) versus children with a PARS score of 67 or higher, i.e., one standard deviation below the mean. This is the recommended and commonly used criteria for the PARS for a community-based population.^{20,21} Similarly, we divided the caregivers into two groups: those with suffering with depression symptoms (CES-D score > 14.2) versus the other caregivers. This cutoff divides the sample at the mean. Because we are using a subset of the 20 item CES-D we elected to use the mean of the distribution to divide the caregivers by depression symptoms. We are also careful in our interpretation of this difference. Because we are using a

subset CES-D we can only determine if caregivers had depression symptoms but not if they were depressed. Twoby-two contingency tables were used to assess whether the indicators of unmet need were related to the mental health status of either the child and/or the caregiver.

We employed instrumental variables for probit estimation as outlined by Ameyia because plan choice was potentially endogenous.²² We estimated probit models for our measures of unmet need where the independent variables were plan choice, child's general health status, child's physical functioning, child's psychological adjustment, child's age and gender, caregiver's age, caregiver's depression measure, household income, caregiver's education level, number of children in the household, and caregiver's marital status. The instruments we used to identify the plan choice equation were: (i) whether the caregiver and the special needs child have the same last name; (ii) a set of dummy variables which indicate the importance of having the special needs child use the same doctor or hospital as other family members; rated as either important, not important, or neutral in selecting a plan. We did not include other measures of children's health status such as the presence of specific chronic conditions and other measures of caregivers' socioeconomic status due to multicollinearity. All of these families were poor or near poor because they were able to meet income requirements for SSI and Medicaid.

We expect that the managed care plan's outreach department would have more success contacting caregivers who have the same last name as the child. For nearly three fourths of the enrollees, the DC Medicaid enrollment records did not contain the parents or caregivers' name. We contend that if the managed care plan's outreach department called the home or sent a letter to the home of a CSHCN eligible for the plan, they would have more success in reaching the caregiver responsible for the child if the caregiver and the child had the same last name. If so, we expect that the child will be more likely to enroll in the MC option. With regard to the second instrument/ identifying variable, if it is important that the special needs child be able to see the same doctor or go to the same hospital as other family members, we expect the child will be more likely to remain in the FFS option. This is because the MC option has a much smaller network of providers than the pool of providers available to children enrolled in FFS.

We hypothesize that neither of these instruments are correlated with unmet need. We tested the validity of our instruments. First, we estimated the plan choice equation with and without the identifying variables. We tested whether the coefficients on the instruments were jointly equal to zero. Essentially we compared the Chi-square statistic for model goodness of fit and the pseudo R^2 s for the models with and without the identifying variables. The test criteria is whether the Chi-square statistic and pseudo R² increases significantly with the identifying variables, if so then they are good instruments for plan choice.^{23,24} The second test evaluated if the instruments were uncorrelated (orthogonal) to the residuals in the second stage equation predicting either unmet need or poor access to care. We evaluated this orthogonality condition by regressing each indicator of unmet need on the dummy variable indicating plan choice, the other exogenous

HEALTH STATUS AND ACCESS TO CARE FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

variables and the set of instruments. We then tested if the coefficients of the instruments were jointly equal to zero. If this was the case, it implies that the instruments were uncorrelated with the residuals of the second stage equation predicting the probability of having an unmet need.²² It also indicated that the instruments provided no new information to predict unmet need.

To test the robustness of our findings we compared the results to bivariate probit estimates, estimates from the Heckman two-step method and simple probits where plan choice was treated as exogenous.^{25,26} The results were not affected by our choice of regression techniques.

Results

The children in our sample were 32% male and 98% African American. They ranged in age from 3 to 16 with 10% between 3 and 5, 28.8% between 6 and 9, 29.2% between 10 and 12 and 32% between 12 and 16. As shown in **Table 1**, the health problems of these children varied. Eighteen percent were in poor or fair health and on average they had 1.28 limitations of activities of daily living. Their average score on the PARS was 79.2. Almost 64% of caregivers reported that their child had mental health problems. Over 60% of caregivers reported that their child had one or more conditions that required therapy. About half of the children had chronic health problems. Over 35 percent of the children had one or more birth defects. Almost one in four caregivers reported their child had one or more acute health problems.

Most often the primary caregiver was the child's natural mother (76.6%). However, grandmother (11.9%), aunt (3.9%), natural father (2.4%), other females (4.4%) and other males (0.8%) were sometimes primary caregivers. The caregivers ranged in age: 17% were under 30, 39.7% were from 30-39; 33.3% were from 40-49; and 9.3% were 50 and over. Their average CES-D score was 14.2 and over 16% had a CES-D score of 28 or more. (See **Table 1**.) Their socioeconomic status was a little higher than a typical TANF recipient. Their average monthly household income was \$1578; 47.2% were employed and only 32% had less than a high school education.

Columns 2-4 of **Table 2** show the bivariate comparisons as to the effects of caregiver mental health status on whether a special needs child experienced different types of unmet health care needs. The results show that caregivers with symptoms of depression were more likely to report their children had unmet health needs than caregivers with none or few symptoms of depression. More than 49% of children whose caregiver reported symptoms of depression experienced one or more unmet health care needs compared to only 35% of children whose caregiver reported few depressive symptoms (p<.01). A similar pattern emerges when one examines specific types of unmet needs. Among

Table 1. Characteristics of Children with Special Health Care Needs and Their Primary Caregiver in the DC Medicaid Program (N=1,043)

Variable	Mean	Standard Deviation for continuous variables
Proportion of CSHCN in Poor or Fair Health	0.181	
ADL INDEX for CSHCN	1.291	1.554
Percent with PAR Score less than 66	0.177	
Proportion of Caregiver's CES-D Score above 14.2	0.397	
Age (in years)	10.440	3.453
Proportion of CSHCN who are Male	0.320	
Proportion of CSHCN enrolled in FFS	0.407	
Proportion of Caregiver's with less than a HS education	0.331	
Proportion of Caregivers with a HS diploma or a GED	0.477	
Proportion of Caregivers with some college education	0.166	
Proportion of Caregivers with a four year college degree.	0.027	
Average Household Monthly Income	\$1573.43	450.80
Proportion of Caregiver below the age of 30	0.206	
Number of Children in Household (including CSHCN)	2.729	1.623
Proportion of Married Caregiver	0.178	
Proportion of Formerly Married (Widowed and Divorced)	0.208	
Proportion of Caregivers and CSHCN who share the same last name	0.541	
Proportion of Caregivers who said it was important that their special needs child be able		
to see the same physician or use the same hospital as other family members	0.676	
Proportion of Caregivers who said it was neither important nor unimportant that their special needs child be able to see the same physician or use the same hospital as		
other family members	0.061	

32

children with caregivers with depressive symptoms, 4.4% had unmet need for well care compared to 2.6% of children whose caregivers did not have symptoms of depression. About 8.1% of children with caregivers who had depressive symptoms encountered an unmet need for either physician or hospital care compared to 4.3% for children whose caregivers were not depressed (p<.01). Among caregivers with depressive symptoms, 12.5% reported that their child experienced an unmet need for mental health services, compared to 7% of caregivers who did not exhibit depressive symptoms (p<.01). Dental unmet needs posed problems for 22.4% of children with depressed caregivers compared to 17.6% of children whose caregivers had no depressive symptoms (p<.05). Close to 30% of children with a depressed caregiver encountered some "other" unmet need (home health, durable medical equipment/supplies, prescribed medications or therapeutic services) compared to only 17.5% of those with few depressive symptoms (p < .01).

In columns 5 and 9 of **Table 2** we report the results from the probit estimations that control for the selection bias linked to plan choice as well as other confounding factors. The percentage of caregivers reporting an unmet health need was 26 to 74% higher for caregivers with symptoms of depression. Adjusting for other factors, caregivers with symptoms of depression were 26.3% more likely to report any unmet need (p<.002), 67.6% more likely to report unmet hospital and physician need (p<.020), 66.1% more likely to report unmet mental health care need (p<.007) and 38.8% more likely to report unmet need for other health care services (p<.006).

Table 3 shows the results of both bivariate and multivariate analyses evaluating the relationship between children's mental health status and whether the child experienced various types of unmet health care needs. The bivariate analyses reveal that children with poor mental health were significantly more likely to experience any unmet need, 54.3% compared to 38.1% of children with good mental health (p<.01). Almost 19% of children with a low PARS score experienced an unmet mental health care need compared to 7.3% of those with a high PARS score (p<.01). Close to 32% of those in poor mental experienced an unmet need for durable medical equipment, home health services, therapy services or prescription drugs, compared to 20.5% of children with better mental health (p<.01). The multivariate analyses, controlling for selection bias linked to plan choice and other confounding factors are reported in columns 5-9 of **Table 3**. These results show that caregivers of children with poor mental health status were 26.2% more likely to report their child had an unmet need (p<.01); 92.3% more likely to report an unmet mental health care need (p<.01); and 95.7% more likely to report an unmet well care unmet need (p < .09).

We asked caregivers the reasons why their children did not receive needed care. The primary reasons caregivers offered were: (i) problems getting a provider (63.3%), (ii) problems with their child's Medicaid eligibility and coverage (18%),

Table 2. Percent of Caregivers Reporting an Unmet Health Care Need for their Child with Special Health Care Needs, by Caregivers' Depression Symptoms

(1) Type of Unmet Need	(2) Percent of Caregivers With No or Few Depression Symptoms	(3) Percent of Caregiver's With Some or Many Depression Symptoms	(4) P-value ^a	(5) Coefficients Associated with having Some or Many Depression Symptoms	(6) Marginal Effects Associated with having Some or Many Depression Symptoms	(7) Predicted Probability of Unmet Needs Evaluated at the Means of the Independent Variables	(8) Percent Change Associated with Depression Symptoms ^b	(9) P-value ^d
Any	35.1	49.2	0.000	0.272	0.106	0.402	26.3	0.002
Well Care	2.6	4.4	0.103	0.269	0.016	0.023	73.4	0.142
Physician or Hospital	4.3	8.1	0.008	0.332	0.035	0.048	67.6	0.020
Mental Health	7.0	12.5	0.002	0.335	0.052	0.078	66.1	0.007
Dental Health	17.6	22.4	0.052	0.189	0.051	0.186	27.7	0.060
Other ^c	17.5	29.8	0.000	0.273	0.080	0.204	38.8	0.006

^a These p-values are from two-by-two chi-squared contingency tables.

^b These figures in columns 5-9 were calculated based on the results of instrument probit regression models where the dependent was a dichotomous measure of unmet need and the independent variables were plan choice, child's general health status, child's physical functioning, child's psychological adjustment, child's age and gender, caregiver's age, caregiver's depression measure, household income, caregiver's education level, number of children in the household, and marital status of the caregiver. Plan choice was treated as endogenous. The instruments were indicators for whether the last names of the child and caregiver matched and the caregivers' rating concerning how important it was for their child to use the same provider as other family members.

^c Other unmet need include home health services, prescribed medicine, medical equipment or supplies, and physical, occupational or speech therapy.

^d These p-values are from regression analyses.

HEALTH STATUS AND ACCESS TO CARE FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Table 3. Percent of Caregivers	Reporting an Unme	et Health Care N	leed for their Child	ren with Special H	ealth Care Needs,	by Child's
PAR Score						

(1) Type of Unmet Need	(2) Low PARS	(3) High PARS	(4) P-value ^a	(5) Coefficients Associated with having a Low PARS score	(6) Marginal Effects Associated with having Low PARS score	(7) Predicted Probability of Unmet Need Evaluated at the Means of the Independent Variables	(8) Percent Change Associated with Low PARS Score ^b	(9) P-value ^d
Any	54.3	38.1	0.000	0.266	0.104	0.402	26.2	0.015
Well Care	6.3	2.7	0.016	0.332	0.022	0.023	95.7	0.086
Physician or Hospital	6.3	5.7	0.747	0.002	0.000	0.048	0.0	0.990
Mental Health	18.9	7.3	0.000	0.412	0.072	0.078	92.3	0.002
Dental Health	21.7	19.1	0.425	0.049	0.013	0.186	7.0	0.687
Other ^c	32.0	20.5	0.001	0.169	0.050	0.204	24.5	0.153

^a These p-values from two-by-two chi-squared contingency tables.

^b These figures in columns 5-9 were calculated based on the results of instrument probit regression models where the dependent was a dichotomous measure of unmet need and the independent variables were plan choice, child's general health status, child's physical functioning, child's psychological adjustment, child's age and gender, caregiver's age, caregiver's depression measure, household income, caregiver's education level, number of children in the household, and marital status of the caregiver. Plan choice was treated as endogenous. The instruments were indicators for whether the last names of the child and caregiver matched and the caregivers' rating concerning how important it was for their child to use the same provider as other family members.

^c Other unmet need include home health services, prescribed medicine, medical equipment or supplies, and physical, occupational or speech therapy.

^d These p-values are from regression analyses.

(iii) they decided to wait and see (16.2%), (iv) it was too inconvenient to get care (9.8%), and (v) they were discouraged by someone else from seeking care (7.4%).

Discussion

Our findings were robust. We were able to control for any selection bias associated with plan choice. Neither the children's mental health status nor their caregiver's mental health status were significant predictors of plan choice. We tested whether there were interactions between mental status and plan choice and our analyses revealed that none exist. With regards to the quality of the instruments, the Chi-square statistic to test whether the instruments are strong predictors of plan choice is 64.2 (p<.01). Moreover, the value of the pseudo R^2 for the plan choice equation with the identifying variables is .06 compared to .015 when the identifying variables are excluded. We also find that the instruments are uncorrelated with each of the indicators of unmet need. Using a test prescribed by Davidson and Mackinnon,²² we find that once we have controlled for plan choice in a model predicting having any unmet need, the instruments provide no new information. The Chi-square statistic to test the joint significance of the three identifying variables in the plan choice equation is 1.8 (p = .6152), which is not statistically significant. This finding indicates that the instruments are orthogonal to the residuals in the general unmet need equation and thus are valid instruments. Results from the Chi-square tests for the other five indicators of unmet need are similar.

Our analyses show that children whose caregivers experience symptoms of depression are significantly more likely to encounter difficulties obtaining needed medical and mental health care services. Furthermore, the findings reported here indicate that children with poor psychological adjustment are significantly more likely to experience unmet needs for medical and mental health care services. The findings suggest that Medicaid officials and Medicaid managed care plans should be concerned about the mental health status of CSHCN and their caregivers. Because we have conducted a cross-sectional analysis, it is not clear in which direction the causality flows. The poor mental health status of CSHCN and their caregivers could hinder their ability to obtain needed care. An alternative explanation is that families with CSHCN could be under sufficient stress that it induces depression symptoms in caregivers and behavioral health problems for CSHCN. Another possible explanation is that caregivers with poor mental health are more likely to complain about the medical services their children receive. However, regardless of the causality what is clear that CSHCN and their caregivers have a need for mental health care. Providing mental health care for CSHCN and their caregivers has the potential for improving overall access for special needs children.

Our analysis focuses on a particular subset of CSHCN, those who were covered by Medicaid and who also qualified for Supplemental Security Income (SSI). The US General

34

Accounting Office estimated that 18% of all CSHSN were eligible for supplemental security income which gives them Medicaid eligibility in most states.^{2,27} Children are eligible for SSI if they are disabled or blinded. According to the Social Security Administration a child is disabled "if he or she has a medically determined physical or mental impairment, which results in marked and severe functional limitation, can be expected to result in death; or has lasted or can be expected to last for a continuous period of not less than 12 months." The program is means tested. For example, for families with a CSHCN and no ineligible children in the household, single parents' gross earnings can not exceed \$2305 monthly and couples' earnings can not exceed \$2849.

Our study has some limitations. First, most of the children in our sample are African-American from one urban area, so the findings may not generalize to children of other races and ethnic groups, special needs children who live in rural areas, or CSHCN from other urban areas. Second, we recognize the possibility that child and caregiver mental health is potentially endogenous. Given that our data are crosssectional, we cannot address this point. Despite these limitations, we believe this study's findings provide new information for policymakers. While this sample focuses on a subset of CSHCN in DC, it renders some insights into the association between the mental health status of CSHCN and their caregivers and the prevalence of unmet health care needs and other access problems. Prior studies that have compared publicly and privately insured CSHCN show no significant differences in the prevalence of unmet needs after controlling for other factors.^{3,6} Our findings suggest that national studies should investigate the extent to which poor mental health status of children's and their caregivers' is a barrier to care for CSHCN. Prior research suggests that low income African American CSHCN are more likely to have unmet needs. Our study provides information about the influence of mental health problems on access to care for this particular vulnerable population. Another advantage of this study is that our measure of unmet need was based on caregivers' reports. These persons were responsible for making care seeking decisions for the children in our sample. Thus, we provide insight on how mental health problems affected their care seeking decisions.

References

- Blumberg SJ, Olson L, Frankel M, Osborn L, Becker CJ, Srinath KP, Giambo P. Design and operation of the National Survey of Children with Special Health Care Needs, 2001. *Vital Health Stat 1*. Jun 2003 (41): 1-136.
- Davidoff AJ. Insurance for Children With Special Health Care Needs: Patterns of Coverage and Burden on Families to Provide Adequate Insurance. *Pediatrics* 2004; **114**(2): 394-403.
- Newacheck PW, McManus M, Fox HB, Hung Y-Y, Halfon N. Access to Health Care for Children With Special Health Care Needs. *Pediatrics* 2000; **105**(4): 760-766.
- McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck PW, Perrin JM, Shonkoff JP, Strickland B. A New Definition of Children With Special Health Care Needs. *Pediatrics* 1998; **102**(1): 137-139.

- Silver EJ, Stein RE. Access to care, unmet health needs, and poverty status among children with and without chronic conditions. *Ambul Pediatr* 2001; 1(6): 314-320.
- Mayer ML, Cockrell Skinner A, Slifkin RT. Unmet Need for Routine and Specialty Care: Data From the National Survey of Children With Special Health Care Needs. *Pediatrics* 2004; 113(2): e109-115.
- Mitchell JM, Gaskin DJ. Do Children Receiving Supplemental Security Income Who Are Enrolled in Medicaid Fare Better Under a Fee-for-Service or Comprehensive Capitation Model? *Pediatrics* 2004; 114(1): 196-204.
- Andersen R, Aday LA. Access to medical care in the U.S.: realized and potential. *Med Care* 1978; 16(7): 533-546.
- 9. Andersen RM. Revisiting the behavioral model and access to medical care: does it matter? *J Health Soc Behav* 1995; **36**(1): 1-10.
- Hughes DC, Johnson KA, Rosenbaum S. Children's Access to Health Care. In: Lillie-Blanton M, Martinez RM, Lyons B, Rowland D, eds. Access to Health Care: Promises and Prospects for Low-Income Americans. Washington DC:The Henry J. Kaiser Family Foundation; 1999: 123-138.
- Brannan AM, Heflinger CA, Foster EM. The role of caregiver strain and other family variables in determining children's use of mental health services. *Journal of Emotional and Behavioral Disorders* 2003; 11(2): 78-92.
- Bussing R, Zima BT, Gary FA, Mason DM, Leon CE, Sinha K, Garvan CW. Social networks, caregiver strain, and utilization of mental health services among elementary school students at high risk for ADHD. *J Am Acad Child Adolesc Psychiatry* 2003; **42**(7): 842-850.
- Bussing R, Zima BT, Gary FA, Garvan CW. Barriers to detection, helpseeking, and service use for children with ADHD symptoms. *J Behav Health Serv Res.* 2003; 30(2): 176-189.
- Bussing R, Gary FA, Mills TL, Garvan CW. Parental explanatory models of ADHD: gender and cultural variations. *Soc Psychiatry Psychiatr Epidemiol* 2003; 38(10): 563-575.
- Rogler LH, Cortes DE. Help-seeking pathways: a unifying concept in mental health care. *Am J Psychiatry* 1993; 150(4): 554-561.
- Costello EJ, Pescosolido BA, Angold A, Burns BJ. A family networkbased model of access to child mental health services. *In Research in Community and Mental Health.* Vol 9: JAI Press Inc.; 1998: 165-190.
- 17. Stein RE, Jessop DJ. Functional status II(R). A measure of child health status. *Med Care* 1990; **28**(11): 1041-1055.
- Okun A, Stein RE, Bauman LJ, Silver EJ. Content validity of the Psychiatric Symptom Index, CES-depression Scale, and State-Trait Anxiety Inventory from the perspective of DSM-IV. *Psychol Rep* 1996; 79: 1059-1069.
- Nguyen HT, Kitner-Triolo M, Evans MK, Zonderman AB. Factorial invariance of the CES-D in low socioeconomic status African Americans compared with a nationally representative sample. *Psychiatry Res* 2004; 126(2): 177-187.
- Pless IB, Feeley N, Gottlieb L, Rowat K, Dougherty G, Willard B. A randomized trial of a nursing intervention to promote the adjustment of children with chronic physical disorders. *Pediatrics* 1994; 94(1): 70-75.
- 21. Witt WP, Kasper JD, Riley AW. Mental health services use among school-aged children with disabilities: the role of sociodemographics, functional limitations, family burdens, and care coordination. *Health Serv Res* 2003; **38**: 1441-1466.
- Davidson R, MacKinnon JG. Estimation and inference in econometrics. New York: Oxford University Press; 1993.
- 23. Bound J, Jaeger JA, Baker RM. Problems with Instrumental Variables Estimation When the Correlation Between the Instruments and the Endogenous Explanatory Variables is Weak. *Journal of the American Statistical Association*. 1995; **90**(3): 443-450.
- Staiger D, Stock JH. Instrumental Variables Regression with Weak Instruments. *Econometrica* 1997; 65(3): 557-586.
- Heckman J. Sample Selection Bias as a Specification Error. Econometrica 1979; 8(1): 153-161.
- 26. Greene WH. *Econometric analysis*. 5th ed. Upper Saddle River, N.J.: Prentice Hall; 2003.
- Scanlon W, Yocom C. Children with Disabilities: Medicaid Can Offer Important Benefits and Services. Washington, DC: US General Accounting Office; 2000. GAO/HEHS-00-152.

HEALTH STATUS AND ACCESS TO CARE FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS