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# The Mental and Physical Health of Mothers of Children with Special Health Care Needs in the United States

Thomas K. Hagerman<sup>1</sup> · Gina P. McKernan<sup>2</sup> · Adam C. Carle<sup>3</sup> · Justin A. Yu<sup>4</sup> · Alyson D. Stover<sup>5</sup> · Amy J. Houtrow<sup>6</sup>

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## Abstract

**Objective** To determine the prevalence of poor mental and physical health among mothers of children with special health care needs (CSHCN) and to determine the association between maternal health and the child's number of special health care needs (SHCN) and severity of ability limitation.

**Methods** We used the combined 2016–2018 National Survey of Children's Health Dataset of 102,341 children ages 0–17 including 23,280 CSHCN. We used regression models to examine the associations of a child's number of SHCN and ability limitations with maternal health.

**Results** Twice as many mothers of CSHCN had poor mental and physical health compared to non-CSHCN (mental 10.3% vs. 4.0%,  $p < .001$ ; physical 11.9% vs 5.0%,  $p < .001$ ). In regression models, increased number of SHCN and severity of activity limitations were associated with significantly increased odds of poor maternal health.

**Conclusions for Practice** Mothers of CSHCN have worse health compared to mothers of non-CSHCN, especially those who experience social disadvantage and those with children with complex SHCN or severe ability limitations. Interventions to improve the health of these particularly vulnerable caregivers of CSHCN are warranted.

**Keywords** Children with special health care needs · Maternal health · Caregivers · Mental health

## Abbreviations

<b>CSHCN</b>	Children with special health care needs
<b>SHCN</b>	Special health care needs
<b>MCHB</b>	Maternal and Child Health Bureau
<b>NSCH</b>	National Survey of Children's Health
<b>FPL</b>	Federal poverty level
<b>ACE</b>	Adverse childhood experience
<b>aOR</b>	Adjusted odds ratio

## Significance Statement

*What is known?* Mothers of children with special health care needs (CSHCN) have added mental and physical health challenges.

*What this study adds* Using an up-to-date nationally representative survey, we found that increasing special health care needs and ability limitation of children was associated

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with poor maternal mental and physical health. We also identified specific subgroups of mothers of CSHCN by demographic and health condition characteristics with a high prevalence of poor health. These results provide a call to action for increased support for the physical and mental health of mothers of CSHCN.

## Introduction

Almost one in five children in the United States ages 0–17 has a special health care need, according to data from the 2016 National Survey of Children's Health (Child and Adolescent Health Measurement Initiative at the Data Resource Center on Child and Adolescent Health). And the prevalence of special health care needs has been increasing in recent decades (van Dyck et al., 2004). The families of children with special health care needs (CSHCN) face a broad array of challenges (Carosella et al., 2018), such as dealing with a health care system perceived as uncoordinated and difficult to navigate (Doig et al., 2009; Ghose, 2003), financial problems related to out-of-pocket costs of the child's care (Kuo et al., 2011), work loss due to the child's health condition (Okumura et al., 2009), difficulty in accessing medical and nonmedical services (Kuo et al., 2011), high levels of stress (Penning & Wu, 2016), and limitations in the adult caregivers' own instrumental activities of daily living (Smith & Grzywacz, 2014). However, these studies are limited by confinement to a single condition or illness severity (Caicedo, 2014, 2015; Lowes et al., 2016; Tseng et al., 2016), specific groups of caregivers (Gravdal Kvarme et al., 2016), or non-US populations (Ausserhofer et al., 2009; Ganjiwale et al., 2016). Additionally, multiple studies have shown the negative impact of maternal mental illness on their children (Baker et al., 2017; Ban et al., 2010).

Substantial evidence suggests that, among CSHCN, families are disproportionately minorities (Cheak-Zamora & Thullen, 2016; Hinojosa et al., 2012), of immigrant status (Gravdal Kvarme et al., 2016; Yu & Singh, 2012), with lower family incomes and less education (Lin & Yu, 2015), and have higher unemployment rates (Cooklin et al., 2015; Earle & Heymann, 2011). Studies using Canadian data from 1994 to 2005 demonstrated that caregivers of CSHCN had increased odds of having a chronic health condition and depressive symptoms (Brehaut et al., 2009, 2011). Evidence remains limited regarding differences in the health of mothers of CSHCN based on socio-demographic characteristics. Therefore, the aim of this study is to examine the prevalence of poor health among mothers of CSHCN and the relation to demographic predictors of maternal health and determine the relationship between the severity of special health care needs (SHCN) and ability limitation (disability) with maternal health. We used a definition of SHCN from the Maternal

and Child Health Bureau that intends to capture a population of children at high risk for chronic physical, developmental, or mental health conditions and/or those requiring above average use of therapies or services (Bethell et al., 2002). Given the increasing evidence to suggest benefits of resilience (McConnell, 2015; Yi-Frazier et al., 2017) and pediatric clinic-based family interventions (Edelstein et al., 2016), an understanding of the subgroups of mothers of CSHCN most at risk for poor health will allow for more targeted interventions and judicious use of scarce resources (Cohen et al., 2011; Pordes et al., 2018).

## Methods

### Dataset

We used a pooled sample of the 2016–2018 NSCH, a survey of 102,341 (50,212 in 2016; 21,599 in 2017; 30,530 in 2018) non-institutionalized US children ages 0–17 from all 50 states and the District of Columbia. The Maternal and Child Health Bureau (MCHB) funded the survey with the purpose of producing national and state-level data on the health of American children. The US Census Bureau and MCHB were responsible for the sampling design. Data were collected from June 2016 to January 2019. About 80% of respondents completed the survey through the internet with the remainder through the postal mail (United States Census Bureau, 2018). Most respondents in the pooled sample were either the child's mother (63.1%) or father (29.0%). We used the provided weights to make the data nationally representative (United States Census Bureau, 2018). This project was exempt by the University of Pittsburgh IRB.

### Outcomes

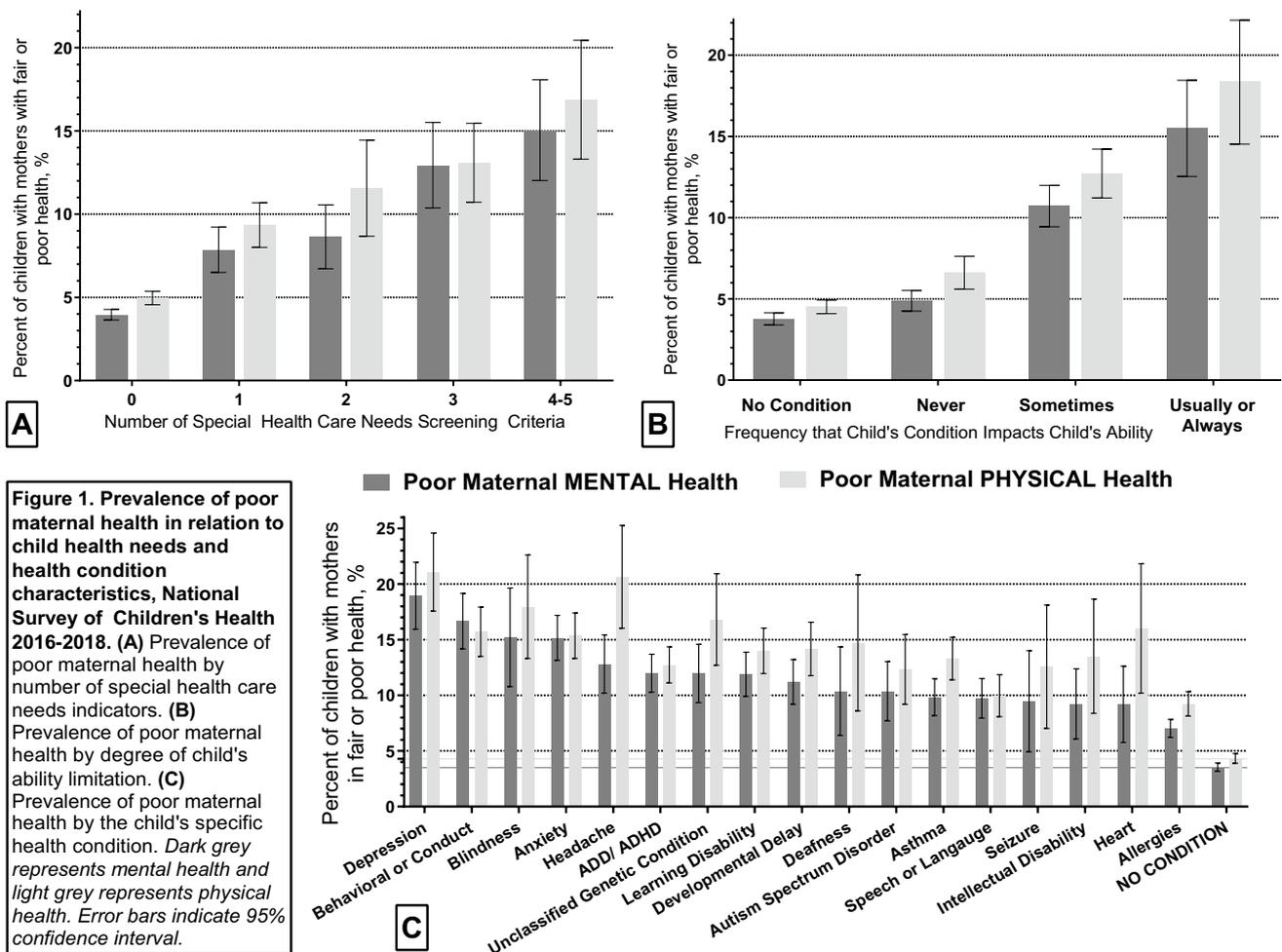
Maternal mental and physical health were addressed by separate survey items. The mother's physical health was rated as "excellent, very good, good, fair, or poor" in response to the question "In general, how is your physical health?" Maternal mental health was assessed similarly with the question "In general, how is your emotional/ mental health?" Responses of "fair" and "poor" were combined due to sample size limitations for a composite outcome of "poor" health, and for simplicity we use the phrase "poor health" to refer to responses of fair or poor. The word mother is used in this paper to represent the female household member(s) that either self-identified or were identified by the other adult respondent as being the child's "biological or adoptive parent, step-parent, or foster-parent." Maternal health was most often rated by the mother herself (69% for both mental and physical health). When the mother was not the respondent, the respondent rated the mental and physical health of

the second adult. If the second adult was the mother, the data were included in these analyses based on our finding that mothers in general had worse self-reported mental and physical health compared to maternal health when reported by a household member other than the mother. Responses for maternal mental and physical health were missing for 0.63% and 0.61%, respectively, of children with mothers in the three-year pooled sample.

### Child-Level Factors

Using the MCHB CSHCN Screener (Bethell et al., 2002), CSHCN were identified by the respondent’s expectation that the child’s condition would last 12 months or longer and at least one positive response to any of the following: (1) current need or use of medication prescribed by a doctor, other than vitamins; (2) need or use of more medical care, mental

health, or educational services than is usual for most children of the same age; (3) limited or prevented ability to do things most children of the same age can do; (4) need or receipt of special therapy, such as physical, occupational, or speech therapy; and (5) any kind of emotional, developmental, or behavioral problem for which the child needs treatment or counseling. All respondents were asked if a doctor or other health care provider had ever told them that the child has one of 26 conditions included in the survey (Fig. 1C). Conditions with less than 500 children in the sample were excluded. Children were considered to have a specific condition if the respondent stated that the child currently had the condition and the condition was expected to last more than 12 months. The child’s overall health status was described as excellent, very good, good, fair, or poor by response to the question, “In general, how would you describe [the child’s] health?” The severity of the child’s ability limitation was rated on a



**Fig. 1** Prevalence of poor maternal health in relation to child health needs and health condition characteristics, National Survey of Children’s Health 2016–2018. **A** Prevalence of poor maternal health by number of special health care needs indicators. **B** Prevalence of poor

maternal health by degree of child’s ability limitation. **C** Prevalence of poor maternal health by the child’s specific health condition. Dark grey represents mental health and light grey represents physical health. Error bars indicate 95% confidence interval

five-point Likert scale from “never” to “always” based on how often in the last twelve months their health condition or problem affected their ability to do things other children their age do. The number of adverse childhood experiences (ACEs) was totaled from responses to questions assessing nine ACEs as established by a technical expert panel at the MCHB (Bethell et al., 2017).

### Family-Level Factors

The child’s family structure was categorized as either two biological or adoptive parents, two parents with at least one non-biological or non-adoptive parent (step-parent), a single mother, or other family structures. Family income was classified into federal poverty level (FPL) categories derived from the Census Bureau’s poverty thresholds which vary by family size and the number of related children under age 18 (United States Census Bureau, 2018). Adults were considered fully employed if the respondent indicated that adults in the house were employed for at least the last 50 weeks of the prior year. Food insecure families were those that “sometimes” or “often” could not afford enough to eat. The total number of moves in a child’s life was summed for a measure of high residential mobility of three or more moves in the child’s lifetime (Busacker & Kasehagen, 2012; Jelleyman & Spencer, 2008).

### Community-Level Factors

An unsafe neighborhood was defined by response of “somewhat” or “definitely disagree” with the statement that the child is safe in the neighborhood. Three detracting neighborhood elements (garbage on streets, rundown housing, and vandalism) and four neighborhood amenities (sidewalks, parks or playgrounds, community center, library or bookmobile) were used to generate composite neighborhood measures in Table 2.

### Statistical Analysis

Descriptive comparisons between child, family, community and health care-factors were conducted and reported with standard errors (Table 1). Chi-square tests in Table 1 were used to determine the statistical significance of demographic differences between CSHCN and non-CSHCN. A  $P$  value  $< 0.05$  was set a priori for all analyses. Bivariate regressions were used in discovery of variables for inclusion in regression analyses. Separate logistic regression models were constructed for maternal mental health, maternal physical health, and the composite variable of both poor maternal mental and physical health. Covariates included in the models were the mother’s age, family structure, mother’s education and birth country, federal poverty level, primary

language, household generation, and the child’s race, sex, and age. Categorical variables were dummy coded to assess effects at each level of the variable. In accordance with guidance from the US Census Bureau, multiple imputation files were used. Income was imputed for 18.6% in 2016, 16.0% in 2017, and 15.3% in 2018 of the children. Stata version 15.0 was used for analyses. (Stata Corp, College Station, TX).

## Results

### Sample Demographics

There were 23,280 CSHCN in the sample with a weighted population prevalence of 18.8% in the United States (Table 1). More than 90% of CSHCN in the sample lived in households with at least one mother. Compared to non-CSHCN, a greater proportion of CSHCN were older, had worse general health, had single mothers, lived in families at lower poverty levels, had 3 or more adverse childhood experiences (ACEs), and lived in communities with many detracting elements.

### Health of Mothers of CSHCN

More mothers of CSHCN than non-CSHCN had poor mental health (10.3% vs. 4.0%,  $p < 0.001$ ) and poor physical health (11.9% vs. 5.0%,  $p < 0.001$ ), (Table 2). Even at the lowest poverty level, twice as many CSHCN had a mother in poor mental and physical health compared to non-CSHCN. More than three times as many CSHCN had mothers in *both* poor mental and physical health (5.6%) compared to non-CSHCN (1.6%,  $p < 0.001$ ). Mothers who self-reported mental health had increased odds of fair or poor mental health [odds ratio, OR 1.55 (95% CI 1.37–1.77)] and fair or poor physical health [OR 1.78 (95% CI 1.52–2.09)] compared to reports of maternal health from household members other than mothers.

Within the group of only CSHCN, 22.8% of CSHCN living in households at less than 100% of the federal poverty level (FPL) had a mother in poor physical health compared to 3.5% of CSHCN at or above 400% of the FPL (Table 2, mental: 16.9% of CSHCN at  $< 100\%$  FPL vs. 4.9% of CHSCN at  $> 400\%$  FPL, all  $p < 0.001$ ). A significantly greater proportion of CSHCN with 3 or more ACEs (26.6% mental, 26.8% physical) had a mother in poor health compared to CSHCN who had zero ACEs (3.2% mental, 5.0% physical; all  $p < 0.001$ ). More single mothers of CSHCN had poor mental and physical health compared to single mothers of non-CSHCN. About 30.8% of CSHCN living in unsafe communities had a mother with poor physical health compared to 10.1% of CSHCN living in safe communities who had a mother with poor physical health.

**Table 1** Sample Characteristics of Children with Special Health Care Needs (CSHCN) and non-CSHCN in the Pooled 2016–2018 National Survey of Children's Health

Characteristics	Non-CSHCN (n=79,061)	CSHCN (n=23,280)	Chi-Square <i>P</i> <i>value</i>	All Children Population %
	Sample % ( <i>n</i> )	Sample % ( <i>n</i> )		
<b>CHILD CHARACTERISTICS</b>				
Gender				
Male	50.1 (39,587)	56.7 (13,190)	< .001	51.1
Female	49.9 (39,474)	43.3 (10,090)		48.9
Age group, years				
0–5	32.6 (25,811)	14.7 (3,420)	< .001	32.2
6–11	29.1 (23,035)	33.8 (7,871)		33.8
12–17	38.2 (30,215)	51.5 (11,989)		33.9
Race/ ethnicity				
White, non-Hispanic	73.9 (54,869)	75.6 (16,425)	< .001	53.8
Black, non-Hispanic	6.0 (4,472)	8.0 (1,735)		13.8
Hispanic	12.3 (9,130)	11.5 (2,492)		26.2
Asian	6.1 (4,524)	3.3 (707)		4.9
Other	1.7 (1,247)	1.6 (357)		1.3
No. of adverse childhood experiences				
0	65.1 (51,491)	45.9 (10,677)	< .001	57.5
1–2	28.1 (22,247)	36.2 (8,430)		32.5
≥ 3	6.7 (5,323)	17.9 (4,173)		10.0
Child's general health poor, fair, or good	3.6 (2,826)	22.9 (5,312)	< .001	10.1
<b>CAREGIVER AND FAMILY CHARACTERISTICS</b>				
Family structure				
2-parent [biological or adoptive]	76.2 (59,223)	64.0 (14,664)	< .001	68.2
2-parent [step-parent]	5.3 (4,088)	8.3 (1,914)		6.2
Single mother	11.7 (9,059)	18.0 (4,124)		16.2
Other	6.8 (5,308)	9.7 (2,222)		9.4
Mother's age, years				
< 35	27.1 (19,340)	18.0 (3,687)	< .001	30.1
35–45	47.0 (33,599)	48.2 (9,844)		49.6
> 45	25.9 (18,521)	33.8 (6,907)		20.4
Combined family income, %FPL				
< 100	10.3 (8,159)	13.3 (3,088)	< .001	20.6
100–199	15.6 (12,326)	17.4 (4,059)		22.0
200–399	31.1 (24,570)	29.5 (6,870)		26.9
≥ 400	43.0 (34,006)	39.8 (9,263)		30.5
Employment status in last year				
Mother unemployed	28.8 (20,601)	31.6 (6,526)	< .001	37.3
Neither primary adult employed	2.2 (1,564)	3.4 (668)	< .001	3.4
Mother's highest education level				
High school graduate/GED or less	14.5 (10,333)	14.5 (2,990)	< .001	26.9
Associate's degree, vocational school, or some college	29.2 (20,861)	32.2 (6,624)		28.8
Bachelor's degree	32.7 (23,349)	29.6 (6,083)		25.7
Master's or Doctorate	23.7 (16,921)	23.7 (4,879)		18.6
Mother born outside USA	15.8 (11,357)	9.2 (1,894)	< .001	23.6
Non-English primary language at home	7.4 (5,799)	3.5 (802)	< .001	14.7
≥ 3 moves in child's life	20.3 (15,541)	31.9 (7,143)	< .001	25.5
Food insecurity in last year	3.3 (2,549)	6.9 (1,572)	< .001	6.1

**Table 1** (continued)

Characteristics	Non-CSHCN (n = 79,061)	CSHCN (n = 23,280)	Chi-Square <i>P</i> <i>value</i>	All Children Population %
	Sample % ( <i>n</i> )	Sample % ( <i>n</i> )		
<b>NEIGHBORHOOD CHARACTERISTICS</b>				
Unsafe community	2.8 (2,128)	4.8 (1,104)	<.001	5.2
≥2 (of 3) detracting elements	6.9 (5,315)	9.0 (2,049)	<.001	9.7
<2 (of 4) amenities	22.4 (17,130)	24.3 (5,481)	<.001	21.1

*n* represents sample total. Population percents are proportions of the weighed national population. See [methods](#) section for definitions of community detracting elements and amenities

%FPL, percentage of the federal poverty level. Discrepancies between sample and population estimates for prevalence of poverty are due to survey weights

Whereas 9.2% of CSHCN meeting only one screening criterion for SHCN had mothers in poor mental health, nearly 18.1% of children meeting four or five criteria had mothers in poor mental health (Fig. 1A). Three times as many mothers of children with the most limited abilities had poor health compared to mothers of children with a condition whose ability was never limited (18.5% vs. 5.5%;  $p < 0.001$ , Fig. 1B). Figure 1C displays the prevalence of poor maternal health among children with specific health conditions. Notably, approximately 21.1% of children with depression and about 15.7% of children with behavioral or conduct problems had a mother in poor health.

## Regression Analyses

### Number of Special Health Care Needs

We identified a positive relationship between the number of a child's special health care needs and the adjusted odds of the mother having poor health (Table 3 Model A). When compared to children *without* special health care needs (non-CSHCN), CHSCN meeting four or five screening criteria had an adjusted odds ratio (aOR) of 3.71 [95% confidence interval (CI) 2.88–4.78] of having a mother in poor mental health (versus good, very good, or excellent), meaning that children meeting four or five screening criteria were 3.7 times more likely than non-CSHCN to have mothers with poor mental health. CSHCN meeting four or five criteria also had an aOR of 2.87 (95% CI 2.18–3.78) of having a mother in poor physical health and an aOR of 4.69 (95% CI 3.31–6.64) of having a mother in *both* poor mental and physical health compared to non-CSHCN. Complete models are presented in Online Appendix A.

### Severity of Ability Limitation

As shown in Model B, increasing severity of a child's ability limitation was positively associated with greater odds of

poor maternal health (Table 3). Compared to children with no health condition, children with the most significant ability limitations had nearly four times the odds of having a mother in poor mental health (aOR = 3.78; 95% CI = 2.94–4.86) and three times the odds of having a mother in poor physical health (aOR = 3.30; 95% CI = 2.51–4.32). Complete models are presented in Online Appendix B.

### Standardized Coefficient Comparison

Shown in Appendices A and B, standardized beta coefficients were used to compare the relative effects of the variables in the models evaluating the association of a child's special health care needs and ability limitation with maternal health. Across all models, the presence of 4 or 5 SCHN criteria, severe ability limitation, and < 100% poverty level had the greatest statistical effects. For instance, in Model B.1 for poor maternal mental health, comparison of the beta coefficients for "usually" or "always limited" (beta = 0.69,  $p < 0.001$ ) and federal poverty level < 100% (beta = 0.34,  $p < 0.01$ ) demonstrates that severe ability limitation had a greater effect in the model than poverty. In addition, severe ability limitation (beta = 0.57,  $p < 0.01$ ) had an effect just smaller than that of poverty (beta = 0.62,  $p < 0.01$ ) but larger than all other variables in the model, as shown in Model B.2 for poor maternal physical health. Family structure, household income, and the mother's education and age (for physical health only) remained independently associated with poor maternal health in all regression models. The child's race and sex were not consistently predictive of poor maternal health.

## Discussion

We examined the mental and physical health of mothers of children with special health care needs using a large population-based sample of children ages 0–17 in the United

**Table 2** Demographics of Children with Special Health Care Needs (CSHCN) and non-CSHCN with Mothers in Fair or Poor Health, National Survey of Children's Health, 2016–2018

	Maternal MENTAL Health Fair/ Poor: % of mothers (95% CI)		Maternal PHYSICAL Health Fair/ Poor: % of mothers (95% CI)	
	non-CSHCN	CSHCN	non-CSHCN	CSHCN
All mothers	5.1 (4.8–5.4)		6.2 (5.9–6.6)	
	4.0 (3.6–4.3)*	10.3 (9.3–11.3)*	5.0 (4.6–5.4)*	11.9 (10.8–13.1)*
Child Characteristics				
Gender				
Male	4.0 (3.5–4.4)*	10.0 (8.7–11.3)*	4.9 (4.3–5.5)*	11.1 (9.6–12.5)*
Female	4.0 (3.5–4.4)*	10.6 (9.0–12.2)*	5.0 (4.5–5.5)*	13.1 (11.2–15.0)*
Age group, years				
0–5	4.3 (3.7–4.9)*	9.1 (6.7–11.5)*	3.8 (3.2–4.5)*	7.4 (5.3–9.5)*
6–11	3.8 (3.3–4.3)*	10.3 (8.6–12.1)*	4.6 (4.0–5.3)*	12.4 (10.4–14.4)*
12–17	3.8 (3.3–4.2)*	10.7 (9.2–12.2)*	6.6 (5.8–7.4)*	13.3 (11.5–15.2)*
Race/ ethnicity				
White, non-Hispanic	3.9 (3.5–4.2)*	8.8 (7.9–9.7)*	3.4 (3.1–3.7)*	9.5 (8.5–10.6)*
Black, non-Hispanic	5.0 (3.9–6.2)*	15.2 (11.3–19.2)*	8.5 (6.8–10.1)*	17.2 (13.4–20.9)*
Hispanic	3.5 (2.7–4.4)*	10.1 (7.5–12.7)*	6.6 (5.4–7.8)*	13.9 (10.4–17.4)*
Asian	2.1 (1.1–3.2)	1.7 (0.7–2.7)	3.0 (1.9–4.2)	2.1 (0.9–3.4)
Other	5.1 (2.7–7.5)	19.4 (7.1–31.8)	8.0 (4.0–12.0)	17.2 (8.0–26.3)
No. of adverse childhood experiences				
0	1.5 (1.3–1.8)*	3.2 (2.3–4.0)*	2.2 (1.9–2.5)*	5.0 (3.8–6.3)*
1–2	6.4 (5.7–7.2)*	10.5 (9.1–11.9)*	8.4 (7.4–9.5)*	12.6 (10.9–14.4)*
≥ 3	16.9 (14.3–19.5)*	26.6 (22.3–30.9)*	16.0 (13.4–18.5)*	26.8 (22.4–31.1)*
Child's general health poor, fair, or good	10.4 (7.7–13.1)*	17.1 (14.2–20.0)*	18.3 (13.8–22.8)	23.8 (20.1–27.4)
Caregiver and Family Characteristics				
Family structure				
2-parent [biological or adoptive]	3.2 (2.9–3.5)*	7.0 (6.1–7.8)*	3.9 (3.4–4.3)*	8.5 (7.4–9.7)*
2-parent [step-parent]	5.8 (4.4–7.1)*	14.2 (9.5–18.8)*	7.4 (5.3–9.6)*	13.8 (9.7–17.9)*
Single mother	7.1 (5.9–8.2)*	16.9 (14.2–19.7)*	9.5 (8.2–10.7)*	19.6 (16.4–22.7)*
Mother's age, years				
< 35	4.9 (4.2–5.5)*	13.0 (10.6–15.4)*	4.9 (4.1–5.7)*	12.3 (9.7–14.8)*
35–45	3.7 (3.2–4.2)*	10.3 (8.8–11.8)*	4.7 (4.2–5.2)*	11.8 (10.1–13.5)*
> 45	3.1 (2.6–3.6)*	8.0 (6.5–9.4)*	5.7 (4.8–6.6)*	12.0 (9.9–14.1)*
Combined family income, %FPL				
< 100	7.0 (6.0–8.0)*	16.9 (14.0–19.9)*	10.3 (8.8–11.9)*	22.8 (19.3–26.4)*
100–199	4.4 (3.6–5.1)*	13.0 (10.6–15.3)*	7.0 (5.9–8.1)*	15.6 (12.6–18.6)*
200–399	3.7 (3.2–4.2)*	8.1 (6.3–10.0)*	3.9 (3.3–4.4)*	8.7 (6.9–10.4)*
≥ 400	2.2 (1.8–2.7)*	4.9 (3.9–5.9)*	1.6 (1.3–1.8)*	3.5 (2.8–4.3)*
Employment status in last year				
Mother unemployed	5.5 (4.9–6.1)*	14.8 (12.8–16.8)*	7.7 (6.8–8.7)*	18.3 (16.1–20.5)*
Neither primary adult employed	7.1 (5.2–9.0)*	16.6 (11.7–21.6)*	12.4 (7.0–17.7)*	25.8 (18.5–33.0)*
Mother's highest education level				
High school grad/GED or less	5.4 (4.7–6.2)*	13.7 (11.4–16.0)*	8.8 (7.6–10.0)*	18.1 (15.3–20.8)*
Associate degree, vocational school, or some college	4.9 (4.3–5.6)*	12.8 (10.6–15.0)*	5.9 (5.2–6.7)*	15.4 (12.8–18.0)*
Bachelor's degree	2.6 (2.2–3.0)*	7.3 (5.5–9.1)*	2.4 (1.9–2.8)*	6.7 (5.0–8.4)*
Master's or Doctorate	2.3 (1.6–3.0)*	4.6 (3.7–5.5)*	1.5 (1.2–1.8)*	3.5 (2.7–4.2)*
Mother born outside USA	2.3 (1.7–2.8)	4.9 (2.9–7.0)	5.2 (4.1–6.2)	8.2 (5.5–10.8)
Non-English primary language at home	2.4 (1.6–3.2)	3.5 (1.8–5.3)	6.5 (4.8–8.1)	7.4 (4.4–10.4)
≥ 3 moves in child's life	5.4 (4.7–6.2)*	15.8 (13.3–18.3)*	7.6 (6.5–8.7)*	18.6 (15.9–21.4)*

**Table 2** (continued)

	Maternal MENTAL Health Fair/ Poor: % of mothers (95% CI)		Maternal PHYSICAL Health Fair/ Poor: % of mothers (95% CI)	
	non-CSHCN	CSHCN	non-CSHCN	CSHCN
Food insecurity in last year	15.2 (12.2–18.1)*	29.1 (23.2–35.0)*	19.8 (15.4–24.3)*	34.7 (27.1–42.3)*
Neighborhood Characteristics				
Unsafe community	11.4 (8.8–14.1)*	22.4 (16.5–28.3)*	16.0 (12.3–19.7)*	30.8 (22.0–39.5)*
≥ 2 (of 3) detracting elements	9.0 (7.4–10.7)*	17.2 (13.3–21.2)*	9.7 (7.8–11.5)*	22.3 (17.4–27.3)*
< 2 (of 4) amenities	4.2 (3.6–4.8)*	11.6 (9.5–13.6)*	6.5 (5.4–7.6)*	16.0 (12.9–19.0)*

\*Indicates statistically significant difference between non-CSHCN and CSHCN

%FPL, percentage of the federal poverty level

Interpretation example: Compared to 5.0% of black non-CSHCN who had a mother with poor mental health, approximately 15.2% of black CSHCN had a mother with poor mental health

**Table 3** Multiple Regression Models Evaluating the Impact of Child Health Characteristics and Care Needs on Maternal Health, National Survey of Children's Health 2016–2018

	Prevalence Population % (sample n)	FAIR/ POOR Rating of Mother's:		BOTH FAIR/ POOR Mental and Physical Health: aOR (95% CI)
		Mental Health aOR (95% CI)	Physical Health aOR (95% CI)	
Number of CSHCN screening criteria (Models A.1-A.3)				
Non-CSHCN (0 screening criteria, Referent)	81.2 (79,061)			
1	7.7 (10,187)	1.93 (1.56–2.38)	1.74 (1.44–2.10)	2.44 (1.81–3.29)
2	4.2 (5,060)	2.08 (1.65–2.63)	2.01 (1.50–2.67)	2.46 (1.74–3.46)
3	3.3 (3,989)	3.10 (2.41–4.00)	2.25 (1.74–2.90)	3.05 (2.21–4.22)
4 or 5	3.6 (4,044)	3.71 (2.88–4.78)	2.87 (2.18–3.78)	4.69 (3.31–6.64)
Severity of child's ability limitation* (Models B.1-B.3)				
No condition (Referent)	66.5 (64,523)			
Never	19.5 (21,016)	1.22 (1.03–1.45)	1.39 (1.14–1.70)	1.02 (0.79–1.32)
Sometimes	10.9 (12,674)	2.78 (2.34–3.30)	2.65 (2.22–3.16)	3.77 (2.94–4.82)
Usually or Always	3.1 (3,202)	3.78 (2.94–4.86)	3.30 (2.52–4.32)	4.41 (3.19–6.09)

Population % estimated from weighted data; sample n = unweighted n; aOR = adjusted odds ratio; 95% CI = 95% confidence interval

Model covariates included family structure, family federal poverty level, mother's age and education, child age, race, and sex

\*Survey item assessing ability limitation asked about the frequency with which the child's health condition(s) or problem(s) affected their ability to do things children of a similar age do

States. We found that mothers of CSHCN had significantly higher rates of poor mental and physical health compared to mothers of non-CSHCN. Mothers experiencing social disadvantage, those with children with multiple SHCN qualifiers, and children with severe ability limitations were significantly more likely to have poor mental and physical health. Specifically, we found that severe ability limitation and the presence of 4 or 5 screening criteria were among the most significant predictors of poor maternal mental and physical health, in some cases more significant than poverty or the mother's education level.

Results from this study indicating that the number of special health care needs is an important predictor of poor

maternal mental and physical health are consistent with a previous Canadian population level study using data collected from 1994 to 2005 (Brehaut et al., 2011). In that study, caregivers of CSHCN meeting 3 or 4 SHCN criteria had nearly three times the odds of having poor health compared to caregivers of non-CSHCN (Brehaut et al., 2011). We found a similar relationship between the number of a SHCN screening criteria and poor maternal mental and physical health. We also found that severe ability limitation was strongly correlated with poor maternal health and in a few cases had a greater strength of association than the family's poverty level and the mother's education level. Our results align with those from Witt and colleagues who

found a negative association between childhood activity limitation and parental mental and general health (Witt et al., 2009). We add to their results by showing an association between increasing ability limitation severity and poor maternal health. Furthermore, we found a stronger association between both mild and severe ability limitation and poor maternal mental and physical health than that shown by Witt and colleagues who use a dichotomous definition of ability limitation (Witt et al., 2009).

We also examined the intersection of a child's SHCN status and demographic factors such as income and race that are well-known to be associated with poor maternal health, data which otherwise to our knowledge was not available. Our data demonstrate that single mothers of children in general have poorer mental and physical health. These disparities are enhanced for single mothers of CSHCN. We also documented significant concordance between poor maternal health and high child ACE exposure, findings consistent with evidence of the intergenerational association of child and parent ACEs (Schofield et al., 2013). In models adjusted for sociodemographic factors including income, our finding that race was not a large driver of maternal health may be due to adjustment for a multitude of other drivers of maternal health (Suglia et al., 2011). Nonetheless, further investigation of the intersectionality between income, race, a child's health status, and maternal health are warranted.

There are several steps that providers, policy makers, and researchers can take to promote maternal health. Providers may start by ensuring that mothers of CSHCN are being screened for poor health. Just as pediatricians would screen for postpartum depression in the post-natal period, pediatric practices may need to expand their role in identifying these challenges in parents of older children. Parents of children with complex medical conditions themselves have called for provider support through psychosocial supports and more effective case management (Carosella et al., 2018). Parents in another qualitative study often described a need for support in the form of relief from caring for their children, supportive counselling, and assistance with making practical arrangements (Hagvall et al., 2016). Clinic partnerships with community services and streamlined connection to government assistance may more effectively utilize all the supports available to these mothers (Brindis & Houtrow, 2018). Clinics and providers can attempt to overcome the stigma associated with mental health care treatment through creation of support groups, facilitation of conversations with family members, and advocacy at community groups and schools (Pinto-Foltz & Logsdon, 2009).

Our results provide a call to action for future research to examine methods of promoting parent resilience and better supporting caregivers of CSHCN and children with disabilities (Bethell et al., 2016; McConnell et al., 2014; Yi-Frazier et al., 2017). For example, interventions originally

studied among caregivers of children with cancer and type I diabetes could be adapted for families caring for CSHCN and children with disabilities (Yi-Frazier et al., 2017).

Policies to incentivize and facilitate clinic integration with community services and partnership between child and adult providers may alleviate the resource and knowledge constraint of addressing maternal health in pediatric clinics. Data from a statewide survey of Medicaid administrators reported that, as of March 2017, 11 states allowed the billing of maternal depression screening under the child's Medicaid. However, only 3 states allowed for the treatment of a parent's depression under the child's Medicaid (Smith, 2017). Policy changes that address barriers and increase reimbursement for such care may enable pediatricians to further participate in the care of entire families. Increased collocation of mental and physical health services in pediatric primary care offices may also offer an opportunity for these providers to participate in the care of parents. Another vital component of reducing the health disparity between mothers of children with and without special health care needs will be to simplify the health care system that parents must navigate and to assist with care coordination (Pordes et al., 2018).

## Limitations

We cannot ascertain the directionality of the associations due to the cross-sectional nature of the NSCH. The study is limited by maternal health measures from a single time point that does not account for the temporal variation in the perception of health (Zajacova & Woo, 2016) nor changes in the health of caregivers of CSHCN that can occur with time (Brehaut et al., 2011). A second limitation of the study is the subjective nature of self-reported mental and physical health. However, similar self-reported subjective measures of health have been shown to be some of the best measures of health outcomes (Fleishman & Zuvekas, 2007; Idler & Angel, 1990) and are predictive of mortality (Gold et al., 1996). The study may also be limited by the minority of proxy-reports for maternal health, though evidence suggests that proxies, compared to self-respondents, may under-report on a variety of health conditions and health services use (Wolinsky et al., 2014, 2016). Furthermore, the sample weights applied were based on the child, not the respondent, so caution is recommended when considering prevalence data for mothers. However, the benefit of knowing the prevalence based on child factors is important as pediatricians may be most aware of the child's conditions and health factors that have been shown here to have independent associations with maternal health.

## Conclusions for Practice

This study provides, to our knowledge, the first up-to-date, US-based, national, quantitative characterization of the marked demographic differences in maternal health for mothers of CSHCN. Results from the study suggest that a child's condition complexity is strongly associated with poor maternal health. And even after accounting for this impact, there are many socioeconomic and demographic factors that predict poor health for mothers of CSHCN. Recognizing the mental and physical health challenges of parents is a crucial aspect of caring for all pediatric patients, especially those most vulnerable including CSHCN and children with sociodemographic disadvantages. Providers are encouraged to go beyond recognition by supporting caregivers in offices and connecting parents to programs and services. Comprehensive family focused care that accounts for and works to address the mental and physical health challenges of mothers of CSHCN should be a priority of clinics, researchers, and policy makers dedicated to improving the lives of CSHCN.

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