



Since January 2020 Elsevier has created a COVID-19 resource centre with free information in English and Mandarin on the novel coronavirus COVID-19. The COVID-19 resource centre is hosted on Elsevier Connect, the company's public news and information website.

Elsevier hereby grants permission to make all its COVID-19-related research that is available on the COVID-19 resource centre - including this research content - immediately available in PubMed Central and other publicly funded repositories, such as the WHO COVID database with rights for unrestricted research re-use and analyses in any form or by any means with acknowledgement of the original source. These permissions are granted for free by Elsevier for as long as the COVID-19 resource centre remains active.

Changes in Use and Access to Care for Children and Youth With Special Health Care Needs During the COVID-19 Pandemic

Kristin Hittle Gigli, PhD, RN, CPNP-AC, & Genevieve Graaf, PhD

Introduction: Children and youth with special health care needs (CYSHCN) are vulnerable to health care disruption, and policies were adopted to mitigate COVID-19-related disruptions. We compare CYSHCN use of and access to care in 2019 to 2020.

Method: Using the National Survey of Children's Health, we identified CYSHCN and assessed differences in health care use, unmet health care needs, frustrations accessing care, and barriers to care using multivariable logistic regression analysis.

Results: The final sample included 17,065 CYSHCN. In the fully adjusted analysis, there was a significant decrease in odds of accessing preventive dental care (adjusted odds ratio [AOR], 0.63; 95% confidence interval [CI], 0.51–0.77) and increased odds of unmet mental health care needs (AOR, 1.34; 95% CI, 1.02–1.77). The inability to obtain an appointment was a barrier that increased during the study period (AOR, 2.77; 95% CI, 1.71–4.46).

Discussion: Novel pandemic related policies may have mitigated negative impacts on health care access for CYSHCN. *J Pediatr Health Care.* (2022) XX, 1–8

Kristin Hittle Gigli, Assistant Professor, College of Nursing and Health Innovation, University of Texas at Arlington, Arlington, TX.

Genevieve Graaf, Assistant Professor, School of Social Work, University of Texas at Arlington, Arlington, TX.

Conflicts of interest: None to report.

Correspondence: Kristin Hittle Gigli, PhD, RN, CPNP-AC, College of Nursing and Health Innovation, University of Texas at Arlington, 411 S. Nedderman Dr., Arlington, TX 76019; e-mail: kristin.gigli@uta.edu.

J Pediatr Health Care. (2022) 00, 1–8

0891-5245/\$36.00

Copyright © 2022 by the National Association of Pediatric Nurse Practitioners. Published by Elsevier Inc. All rights reserved.

<https://doi.org/10.1016/j.pedhc.2022.09.008>

KEY WORDS

Children and youth with Special Health Care Needs, COVID-19 pandemic, access to care

INTRODUCTION

The COVID-19 pandemic profoundly affected child health and well-being. Disruptions in school and alterations in socialization contribute to worsening child mental health (Cutler et al., 2022; Howard-Jones et al., 2022; Shankar et al., 2022). There were also changes in the use of pediatric primary care, including decreased use of preventive care and receipt of routine vaccinations (Lebrun-Harris et al., 2022; Schweiberger et al., 2021). These changes culminated in significant increases in unmet pediatric health care needs.

A focal subpopulation of nearly 14 million children is children and youth with Special Health Care Needs (CYSHCN). These CYSHCNs have a diverse range of health conditions and care needs, but all have one or more chronic physical, developmental, behavioral, or emotional conditions and require more health services than the average child (Health Resources and Services Administration, 2021). However, although CYSHCNs have greater needs for health services, they routinely have higher rates of unmet needs with notable age and racial disparities (Ghandour et al., 2022; Kuo et al., 2014). In addition, most CYSHCNs do not receive care in a functioning health system (Ghandour et al., 2022; Yu et al., 2021). As a result, CYSHCN had increased vulnerability to COVID-19-related disruptions and changes in health care delivery (Mitchell, 2021). In response, state and federal policymakers attempted to mitigate the effects of the COVID-19 pandemic on access to care for CYSHCN through multiple legislative and regulatory changes (Table 1; Sillow-Carroll et al., 2021).

TABLE 1. Illustrative legislative, regulatory, and executive policy responses address pediatric access to care during the COVID-19 pandemic

Area of intended policy intervention	Policy
Telehealth use	<ul style="list-style-type: none"> • Coronavirus Preparedness and Response Supplemental Appropriations Act • Coronavirus Aid, Relief, and Economic Security Act • Consolidated Appropriations Act of 2021 • American rescue plan act of 2021 • Improving rural health and telehealth access executive order
Medicaid and Children's Health Insurance Program eligibility or payment	<ul style="list-style-type: none"> • Families First Coronavirus Response Act • Coronavirus Aid, Relief, and Economic Security Act • Section 1,135 waiver (50 states and Washington DC) • Disaster-Relief Medicaid State Plan Amendment (47 states and Washington DC) • Children's Health Insurance Plan State Plan Amendment (35 states) • Appendix K of Section (1915) (c) Home and Community-Based Services waivers (50 states and Washington, DC) • COVID-19 Public Health Emergency Demonstration Section 1,115 waivers (11 states)
Mental Health Care delivery Workforce availability	<ul style="list-style-type: none"> • American Rescue Plan Act of 2021 • Paycheck Protection and Health Care Enhancement Act • 2021 Medicare physician fee schedule final rule • Governors' Executive Orders addressing state-scope of practice (23 states)

Poghosyan et al. (2022); Silow-Carroll et al. (2021).

However, it is unclear how effective these policy changes were in realizing access to care for CYSHCN. To address this knowledge gap, we evaluated changes in access to care for CYSHCN during the first year of the COVID-19 pandemic and examined barriers to accessing needed health services to evaluate the impact of the COVID-19-related policy changes.

METHODS

This study drew on pooled 2019–20 data from the publicly available National Survey of Children's Health (NSCH). This population-based survey is conducted annually by the U.S. Census Bureau for the U.S. Department of Health and Human Services, Health Resources and Services Administration, and Maternal and Child Health Bureau. The survey data offers detailed information on children's health and mental health status, health care and support service experiences, and social and environmental context. It is weighted to enable the generation of state and nationally representative estimates representing the population of noninstitutionalized children aged 0–17 years living in housing units in the United States (Ghandour et al., 2018). This analysis focused on the subsample of CYSHCN within the NSCH. The NSCH uses the Child with Special Health Care Needs screening tool, described in detail elsewhere (Bethell et al., 2015), to identify CYSHCN. Survey design and administration are also detailed elsewhere (Ghandour et al., 2018).

Key Variables

The dependent variables used in this study, the survey item measuring them, and the structure of each is listed in Supplementary Table 1, which also describes the structure of two control variables: whether the child has emotional, behavioral, and developmental problems and complexity of needs. Additional control variables included child demographics, sex, age, race, and ethnicity. Family resources covariates included caregiver education level, household language, family, type of child's health insurance, and continuity of child's health insurance. The predictor variable in this analysis was the year of data collection.

Analysis

The study sample included all children in the datasets, years 2019 and 2020, who met the criteria for having special health care needs ($n = 17,065$). Analyses were conducted in Stata/MP (version 16.1; StataCorp LLC, College Station, TX) and accounted for the survey's complex sampling design and weighting, allowing for national estimates in analytic outcomes. Less than 5% of the sample was missing nonimputed data for other individual covariates and outcome variables, and these observations were excluded from the multivariable analysis. Up to 10% of observations with missingness can be dropped without compromising the national representativeness of the data, its weighing, and related analytic outcomes (Langkamp et al., 2010).

Among CYSHCN, we conducted a univariate and bivariate analysis to assess for significant differences in frequencies of all dependent variables and covariates comparing CYSHCN across 2019 and 2020. Chi-square tests estimated

the significance of differences across years. Fixed effects multivariable logistic regression models estimated the association between change in a year and reported unmet health care needs and difficulties or frustrations in accessing care or referrals for care. Bivariate analysis and fixed effects multivariable logistic regression analysis examined the experience of specific barriers to health care among CYSHCN with any unmet need for health care ($n = 1,207$).

RESULTS

Children and Youth Characteristics

There were 17,065 CYSHCN included in the 2019 and 2020 survey samples. The characteristics of CYSHCN were generally comparable between 2019 and 2020, with two notable exceptions (Table 2). In 2020, CYSHCN had more ongoing emotional, behavioral, or developmental problems (45.1% vs. 50.6%, $p = .001$) and more complexity of needs (70.4% vs. 75.1%, $p = .001$). There were no significant changes in

insurance coverage type or continuity and household income from 2019 to 2020.

Health Care Use and Access to Care

In unadjusted analysis, from 2019 to 2020, there was a statistically significant decrease in rates of preventive medical visits (89.8% in 2019 to 87.5% in 2020, $p = .04$) and preventive dental visits (85.4% in 2019 to 78.5% in 2020, $p < .001$; Table 3). There was also a statistically significant increase in the rate of unmet mental health care needs (5.1% in 2019 to 7.0% in 2020, $p = .01$). There were no statistically significant changes with respect to unmet need for health care, use of specialty care, or frustration obtaining medical services.

In the fully adjusted analysis, significant differences in use of preventive dental care (adjusted odds ratio [AOR], 0.63; 95% CI, 0.51–0.77; $p < .001$) persisted as did unmet health care needs (AOR, 1.34; 95% confidence interval, 1.02–1.77; $p = .04$) from 2019 to 2020 (Table 4).

TABLE 2. Demographic characteristics of children and youth with special health care need included in the 2019 and 2020 National Survey of Children's Health

Characteristic	Total (N = 17,065) ^a N (weighted %)	2019 (n = 7,021) Weighted %	2020 (n = 10,044) Weighted %	p Value
Age (years)				
0–5	2,391 (17.5)	17.4	17.5	.97
6–11	5,708 (37.0)	36.8	37.1	
12–17	8,966 (45.6)	45.8	45.4	
Sex (male)	9,696 (58.2)	58.3	58.1	.91
Race				
White, non-Hispanic	11,817 (52.3)	52.8	51.9	.80
Black, non-Hispanic	1,296 (16.0)	15.6	16.4	
Hispanic	2,023 (22.3)	21.9	22.6	
Other/multiracial	1,929 (9.4)	9.7	9.2	
Insured continuous in the past 12 months (yes)	16,099 (93.5)	93.6	93.5	.88
Type of insurance				
Public	4,558 (36.4)	36.6	36.6	.57
Private	10,494 (51.0)	51.6	51.6	
Public and private	1,228 (8.6)	8.3	8.3	
Not insured	576 (3.9)	3.5	3.5	
Child has ongoing emotional, behavioral, or developmental problems (yes)	7,895 (47.9)	45.1	50.6	.001
Complexity of needs				
Less complex needs	4,903 (27.2)	29.6	24.9	.001
More complex needs	12,162 (72.8)	70.4	75.1	
Parent education level				.31
Less than high school	2,630 (27.1)	26.2	27.9	
More than high school	14,435 (72.9)	73.8	72.1	
Family structure				.83
Single parent or other structure	4,920 (33.9)	33.7	34.1	
Two parent family	11,778 (66.1)	66.3	65.9	
Household language				.37
English	16,378 (92.7)	93.2	92.2	
Not English	616 (7.3)	6.8	7.8	
Household income, % of federal poverty level				.35
0–99	2,326 (21.6)	22.7	20.6	
100–199	3,017 (21.7)	21.2	22.1	
200–399	5,252 (27.8)	26.9	28.8	
≥ 400	6,470 (28.9)	29.3	28.5	

^aVariable sample size does not always equal the total sample size because of variation in response rate across variables.

TABLE 3. Health care use, access to care, and experiences obtaining care among children and youth with special health care needs from 2019 to 2020

Outcome	Total ^a (N = 17,065) N (Weighted %)	2019 (n = 7,021) Weighted %	2020 (n = 10,044) Weighted %	p Value
At least one preventive care visit				.04
No	1,776 (11.4)	10.3	12.5	
Yes	15,216 (88.6)	89.8	87.5	
At least one preventive dental visit				< .001
No	2,292 (18.1)	14.6	21.5	
Yes	14,587 (81.9)	85.4	78.5	
Any unmet health care need				.82
No	15,797 (91.2)	91.4	91.1	
Yes	1,212 (8.8)	8.6	8.9	
Any unmet mental health care need				.01
No	16,042 (93.9)	94.9	93.0	
Yes	952 (6.1)	5.1	7.0	
Unmet need for specialist care				.56
No	16,379 (94.6)	94.3	94.9	
Yes	573 (5.4)	5.7	5.2	
Experienced frustration in accessing care				.27
No	15,210 (86.9)	86.2	87.7	
Yes	1,819 (13.1)	13.8	12.4	
Experienced difficulty obtaining referrals for specialist care				.49
No	15,511 (90.0)	90.4	89.7	
Yes	1,458 (10.0)	9.6	10.3	
Experienced difficulty accessing specialist care				.94
No	14,915 (88.0)	87.9	88.0	
Yes	1,969 (12.0)	12.1	12.0	

^aVariable sample size does not always equal total sample size because of variation in response rate across variables.

Parents of CYSHCN reported no significant change in accessing preventive care and reported no significant changes in unmet needs for health care or specialist care. Further, rates of reported frustration in accessing care, difficulty in accessing specialist care, and difficulty obtaining referrals did not change significantly among parents of CYSHCN (Supplementary Table 2).

We identified characteristics associated with decreased use and access to care and protective characteristics associated with receipt of needed care. Regarding preventive health and dental care, CYSHCN were statistically significantly less likely to receive preventive care if they were older or uninsured (Table 4). In addition, Black CYSHCN had greater odds of unmet mental health care, and Black and Hispanic CYSHCN had a greater unmet need for specialist care ($p \leq .05$). However, greater parental education and household income were associated with statistically significantly greater odds of receiving preventive health and dental care ($p < .01$).

Furthermore, CYSHCNs who did not have continuous insurance coverage were more likely to have unmet needs for health care (AOR, 3.81; $p < .001$) and unmet needs for specialist care (AOR, 1.97; $p = .005$). The presence of an ongoing emotional, behavioral or developmental problem was associated with greater odds of unmet health care needs (AOR, 2.26; $p < .001$), unmet mental health care needs (AOR, 2.97; $p < .001$), and unmet needs for specialist care (AOR, 2.06; $p = .002$). In addition, CYSHCN had greater

odds of unmet mental health care if they had more complex needs (AOR, 1.92; $p = .02$).

There was greater frustration in obtaining care for CYSHCN among key populations (Supplementary Table 2). Specifically, CYSHCN who were not continuously insured had statistically significantly greater frustration accessing care (AOR, 3.01), obtaining referrals for specialist care (AOR, 3.49), and accessing specialist care (AOR, 3.26; all $p < .001$). Those CYSHCN with more medical complexity had statistically significantly greater frustration accessing care (AOR, 1.85; $p = .02$), obtaining referrals for specialist care (AOR, 2.73; $p < .001$), and accessing specialist care (AOR, 3.25; $p < .001$).

Barriers to Health Care

Among those who reported unmet health care needs ($n = 1,207$), the most reported barriers to care in 2019 and 2020 were problems with the cost of care and problems obtaining an appointment (Table 5). From 2019 to 2020 there were statistically significant changes in unadjusted odds of CYSHCNs' inability to obtain an appointment (odds ratio, 2.75; $p < .001$) and offices being closed (odds ratio, 4.18; $p < .001$). However, when adjusting for patient and family characteristics, CYSHCN with unmet health care needs only had statistically greater odds of being unable to obtain an appointment (AOR, 2.77; $p < .001$). Notably, from 2019 to 2020, among CYSHCN with unmet health care needs, there was a statistically significant decrease in

TABLE 4. Results of the logistic regression analyses examining health care use and access to care from 2019 to 2020 among children and youth with special health care needs

Characteristic	≥ 1 Preventive care visit		≥ 1 Preventive dental visit		Any unmet health care need		Any unmet mental health care need		Unmet need for specialist care	
	OR (95% CI)	p Value	OR (95% CI)	p Value	OR (95% CI)	p Value	OR (95% CI)	p Value	OR (95% CI)	p Value
Year										
2019	Ref		Ref		Ref		Ref		Ref	
2020	0.84 (0.67–1.05)	.12	0.63 (0.51–0.77)	< .001	1.07 (0.79–1.46)	.65	1.34 (1.02–1.77)	.04	0.83 (0.57–1.22)	.33
Age (years)										
0–5	Ref		Ref		Ref		Ref		Ref	
6–11	0.59 (0.40–0.88)	.01	4.43 (3.39–5.78)	< .001	1.07 (0.64–1.80)	.79	1.51 (0.95–2.39)	.08	1.95 (1.13–3.38)	.02
12–17	0.39 (0.26–0.57)	< .001	3.23 (2.47–4.21)	< .001	1.15 (0.68–1.96)	.60	1.51 (1.00–2.30)	.05	1.39 (0.78–2.49)	.26
Sex										
Male	Ref		Ref		Ref		Ref		Ref	
Female	1.31 (1.05–1.64)	.02	1.08 (0.88–1.33)	.48	1.19 (0.86–1.64)	.30	1.11 (0.85–1.44)	.44	1.27 (0.85–1.89)	.24
Race										
White, non-Hispanic	Ref		Ref		Ref		Ref		Ref	
Black, non-Hispanic	1.17 (0.82–1.68)	.39	0.77 (0.58–1.03)	.08	0.81 (0.53–1.24)	.32	1.47 (1.00–2.16)	.05	1.60 (1.00–2.57)	.05
Hispanic	0.87 (0.60–1.26)	.46	0.91 (0.66–1.27)	.91	1.13 (0.67–1.90)	.65	0.83 (0.55–1.25)	.37	2.22 (1.18–4.17)	.01
Other/multiracial	0.77 (0.56–1.05)	.10	0.96 (0.72–1.29)	.96	1.30 (0.81–2.09)	.28	1.38 (0.80–2.36)	.25	1.36 (0.78–2.38)	.28
Insured continuous in past 12 months										
Yes	Ref		Ref		Ref		Ref		Ref	
No	1.15 (0.59–2.24)	.69	0.63 (0.34–1.16)	.14	3.81 (2.02–7.17)	< .001	1.81 (0.95–3.46)	.07	1.97 (0.99–3.93)	.05
Type of insurance										
Private	Ref		Ref		Ref		Ref		Ref	
Public	1.18 (0.88–1.60)	.27	0.75 (0.54–1.04)	.08	0.97 (0.60–1.56)	.89	1.10 (0.77–1.56)	.60	0.72 (0.42–1.23)	.23
Public and private	0.79 (0.51–1.24)	.31	0.81 (0.54–1.21)	.30	1.41 (0.74–2.68)	.30	0.98 (0.53–1.84)	.96	1.02 (0.50–2.08)	.96
Not insured	0.41 (0.19–0.86)	.02	0.53 (0.26–1.09)	.08	0.89 (0.40–1.98)	.78	1.14 (0.48–2.71)	.76	0.91 (0.37–2.23)	.83
Child has ongoing emotional, behavioral, or developmental problem										
No	Ref		Ref		Ref		Ref		Ref	
Yes	0.84 (0.65–1.10)	.20	0.90 (0.70–1.16)	.41	2.26 (1.46–3.50)	< .001	2.97 (2.08–4.24)	< .001	2.06 (1.32–3.22)	.002
Complexity of needs										
Less complex needs	Ref		Ref		Ref		Ref		Ref	
More complex needs	1.06 (0.78–1.43)	.72	0.96 (0.73–1.27)	.79	1.56 (0.83–2.94)	.17	1.92 (1.11–3.30)	.02	1.20 (0.55–2.63)	.65
Parent education level										
Less than high school	Ref		Ref		Ref		Ref		Ref	
More than high school	1.70 (1.28–2.25)	< .001	1.79 (1.36–2.36)	< .001	1.28 (0.76–2.15)	.36	1.26 (0.90–1.78)	.18	10.1 (0.67–1.51)	.97
Family structure										
Single parent or other	Ref		Ref		Ref		Ref		Ref	
Two parent family	1.57 (1.22–2.02)	< .001	0.86 (0.68–1.09)	.21	1.05 (0.76–1.45)	.79	0.92 (0.67–1.26)	.59	0.98 (0.65–1.48)	.92

(continued on next page)

TABLE 4. (Continued)

Characteristic	≥ 1 Preventive care visit		≥ 1 Preventive dental visit		Any unmet health care need		Any unmet mental health care need		Unmet need for specialist care	
	OR (95% CI)	p Value	OR (95% CI)	p Value	OR (95% CI)	p Value	OR (95% CI)	p Value	OR (95% CI)	p Value
Household language										
Not English	Ref		Ref		Ref		Ref		Ref	
English	1.12 (0.68–1.86)	.66	0.68 (0.41–1.14)	.15	1.29 (0.57–2.94)	.54	0.94 (0.47–1.90)	.87	1.01 (0.43–2.38)	.99
Household income, % of federal poverty level										
0–99	Ref		Ref		Ref		Ref		Ref	
100–199	1.30 (0.93–1.80)	.12	1.00 (0.73–1.37)	.99	1.13 (0.63–2.02)	.69	0.64 (0.42–0.98)	.04	0.72 (0.46–1.11)	.14
200–399	1.21 (0.85–1.73)	.28	1.23 (0.89–1.71)	.22	0.84 (0.46–1.51)	.56	0.79 (0.51–1.23)	.30	1.03 (0.55–1.94)	.93
≥ 400	1.67 (1.15–2.44)	.01	2.01 (1.41–2.88)	< .001	0.53 (0.28–0.99)	.05	0.71 (0.41–1.21)	.20	0.57 (0.29–1.11)	.10

Note. CI, confidence interval; OR, odds ratio; Ref, reference.

TABLE 5. Unadjusted and adjusted rates of parent-reported barriers to health care for CYSHCNs with unmet health care needs (2019–20)

Barriers to health care	2019 (n = 443)	2020 (n = 707)	Change from 2019–2020		Adjusted change from 2019–2020	
	Weighted % (95% CI)	Weighted % (95% CI)	OR (95% CI)	p Value	Adjusted OR ^a (95% CI)	p Value
Ineligible for services	40.6 (30.0–52.1)	29.3 (20.8–39.5)	0.61 (0.32–1.16)	.13	0.53 (0.30–0.91)	.02
Unable to obtain an appointment	41.3 (32.0–51.3)	65.9 (56.5–74.3)	2.75 (1.56–4.85)	< .001	2.77 (1.71–4.46)	< .001
Problems getting transportation	15.8 (10.4–23.2)	16.9 (9.8–27.6)	1.09 (0.49–2.39)	.84	0.82 (0.43–1.59)	.56
Problems with the cost of care	51.6 (40.9–61.2)	46.4 (36.9–56.1)	0.81 (0.45–1.45)	.48	0.75 (0.46–1.22)	.25
Service was unavailable	32.9 (24.6–42.4)	38.4 (28.9–48.9)	1.28 (0.71–2.30)	.42	1.13 (0.68–1.88)	.64
The office was not open	12.6 (8.3–18.9)	37.7 (28.3–48.1)	4.18 (2.21–7.90)	< .001	4.58 (2.46–8.52)	.85

Note. CYSHCN, children and youth with special health care needs; CI, confidence interval; OR, odds ratio.

^aAdjusted odds ratios adjusted for child sex, age, race, insurance continuity and type, presence of an emotional, behavioral, or developmental problem, complexity of needs, parent education, family structure, language, and household income.

odds of being ineligible for services (AOR, 0.52; $p = .02$). There were no significant changes in other reported barriers to care including cost or service availability.

DISCUSSION

In response to the COVID-19 pandemic, policymakers implemented various policies to prevent care disruptions for vulnerable populations, including CYSHCN. This evaluation of the use of preventive care and access to care from 2019 to 2020 examines the initial impact of the COVID-19 pandemic on CYSHCN. Although CYSHCN was largely shielded from significant impacts during this time, we found important changes in the use of and access to care and barriers to care that should inform future policy interventions.

In the first year of the pandemic, CYSHCN had a statistically significant decrease in preventive dental visits and increased unmet mental health care needs. Notably, these trends were consistent with trends in the general pediatric population, not unique to CYSHCN (Lebrun-Harris et al., 2022). As such, we believe that the policies implemented to support CYSHCN generally achieved their goal of mitigating the effect of the COVID-19 pandemic on the use of and access to care. Furthermore, given the vulnerability of CYSHCN to care disruptions, we believe these findings are reassuring that the identified declines in use and access are not a unique challenge for CYSHCN but reflect challenges to providing adequate health care to all children in the United States.

Within the population of CYSHCN, we found disparities in the use of and access to care among key subgroups. The disparities identified were not novel findings but are consistent with widely known prepandemic barriers to care for CYSHCN (Cheak-Zamora & Thullen, 2017; Glasgow & Van Voorhees, 2017; Rosen-Reynoso et al., 2016; Vish & Stolfi, 2020). As policymakers consider future interventions to ensure care for CYSHCN, targeted strategies to support key subpopulations can help close service gaps. Specifically, as CYSHCN age, their use of preventive care decreases, and the expansion of evidence-based programs, including school-based health care and nonclinical services (i.e., language services, transportation), are strategies to apportion care to these children (Arenson et al., 2019; Yue et al., 2019). In addition, CYSHCN with ongoing emotional, behavioral or developmental problems and greater complexity had greater unmet care needs. Although opportunities to address improved access for this population exist through the expansion of targeted Medicaid Home and Community-Based Services waivers and changes in financial reimbursement structures that account for the complexity of care, future work should examine which strategies are most effective in facilitating CYSHCNs' access to needed care.

Importantly, the pandemic highlighted systemic disparities in health care access and outcomes in the United States (Centers for Disease Control and Prevention, 2021; Lopez, Hart, & Katz, 2021). Although we were only able to look at differences among subpopulations in use of and access to care, as more years of data are available, analysis of clinical

and demographic variation in changes in services access and use will be vital for assessing the differential impacts of the COVID-19 pandemic on these key subgroups. Specifically, we anticipate that the pandemic had an unequal impact on minority and lower-income populations of CYSHCN and CYSHCN with emotional, behavioral, or developmental conditions. Enumerating disparities will be important to highlight to justify the need for policy, system, or practice changes that may address any observed disparities.

We identified important changes in barriers to care among CYSHCN who had unmet health care needs. Ineligibility for services declined significantly from 2019 to 2020 and maybe the direct result of numerous pandemic-related policies (Table 1) to support CYSHCN. Continuing these policies beyond the end of the public health emergency may be a mechanism to sustain gains in access to care for CYSHCN. However, children who had coverage gaps had greater unmet health care and specialty care needs; additional exploration of barriers in this group can inform further policy changes and health system interventions aimed at preventing coverage interruptions.

The inability to obtain an appointment was the only barrier that became more pronounced from 2019 to 2020. This may be the result of the initial response to the pandemic with lockdown policies that closed offices and led to a transition period with wider implementation of telehealth (Levy, 2021). Evaluation of the persistence in reports of an inability to obtain should be a future priority to assess the long-term impact of the COVID-19 pandemic on access to care.

Limitations

This study has several limitations. First, the data do not allow causal inference of the effect of the COVID-19 pandemic on CYSHCN use of and access to care. Data was collected for the 2020 NSCH from June 2020 to January 2021. As a result, the 2020 survey is unlikely to capture the full effect of the pandemic on the use and access to care. However, there is some indication that changes in pediatric health care may be limited to the beginning of the pandemic (Schweiberger et al., 2021). As such, future research should include years of data to evaluate the persistence of pandemic patterns. In addition, the NSCH collects self-reported data introducing the possibility of recall bias and inaccuracy in the report. Specifically, determining what constitutes an unmet need may differ among families and health care providers and is a limitation of this data.

Conclusions

Although CYSHCN had declines in preventive dental visits and increased unmet mental health care needs, novel health policies adopted in response to the COVID-19 pandemic may have mitigated negative impacts on this vulnerable population. CYSHCNs with unmet health care needs saw improvements in their eligibility for care. Future work should examine how the COVID-19 pandemic influenced disparities in the use of and access to care among subgroups of CYSHCN,

including minorities, low-income families, and those with emotional, behavioral, or developmental problems.

SUPPLEMENTARY MATERIALS

Supplementary material associated with this article can be found in the online version at <https://doi.org/10.1016/j.pedhc.2022.09.008>.

REFERENCES

- Arenson, M., Hudson, P. J., Lee, N., & Lai, B. (2019). The evidence on school-based health centers: A review. *Global Pediatric Health, 6*, 2333794X19828745.
- Bethell, C. D., Blumberg, S. J., Stein, R. E., Strickland, B., Robertson, J., & Newacheck, P. W. (2015). Taking stock of the CSHCN screener: A review of common questions and current reflections. *Academic Pediatrics, 15*(2), 165–176.
- Centers for Disease Control and Prevention. (2021). Impact of racism on our nation's health. <https://www.cdc.gov/healthequity/racism-disparities/impact-of-racism.html>
- Cheak-Zamora, N. C., & Thullen, M. (2017). Disparities in quality and access to care for children with developmental disabilities and multiple health conditions. *Maternal and Child Health Journal, 21*(1), 36–44.
- Cutler, G. J., Bergmann, K. R., Douplik, S. K., Hoffmann, J. A., Neuman, M. I., Rodean, J., Zagel, A. L., & Zima, B. T. (2022). Pediatric mental health emergency department visits and access to inpatient care: A crisis worsened by the COVID-19 pandemic. *Academic Pediatrics, 22*(6), 889–891.
- Ghandour, R. M., Hirai, A. H., & Kenney, M. K. (2022). Children and youth with special health care needs: A profile. *Pediatrics, 149* (Suppl. 7), e2021056150.
- Ghandour, R. M., Jones, J. R., Lebrun-Harris, L. A., Minnaert, J., Blumberg, S. J., Fields, J., Bethell, C., & Kogan, M. D. (2018). The Design and implementation of the 2016 National Survey of Children's Health. *Maternal and Child Health Journal, 22*(8), 1093–1102.
- Glassgow, A. E., & Van Voorhees, B. (2017). Behavioral health disparities among children and youth with special health care needs. *Pediatric Annals, 46*(10), e382–e386.
- Health Resources and Services Administration. (2021). Children and Youth with Special Health Care Needs (CYSHCN). <https://mchb.hrsa.gov/programs-impact/focus-areas/children-youth-special-health-care-needs-cyshcn>
- Howard-Jones, A. R., Bowen, A. C., Danchin, M., Koirala, A., Sharma, K., Yeoh, D. K., Burgner, D. P., Crawford, N. W., Goeman, E., Gray, P. E., Hsu, P., Kuek, S., McMullan, B. J., Tosif, S., Wurzel, D., & Britton, P. N. (2022). COVID-19 in children: I. Epidemiology, prevention and indirect impacts. *Journal of Paediatrics and Child Health, 58*(1), 39–45.
- Kuo, D. Z., Goudie, A., Cohen, E., Houtrow, A., Agrawal, R., Carle, A. C., & Wells, N. (2014). Inequities in health care needs for children with medical complexity. *Health Affairs, 33*(12), 2190–2198.
- Langkamp, D. L., Lehman, A., & Lemeshow, S. (2010). Techniques for handling missing data in secondary analyses of large surveys. *Academic Pediatrics, 10*(3), 205–210.
- Lebrun-Harris, L. A., Sappenfield, O. R., & Warren, M. D. (2022). Missed and delayed preventive health care visits among US children due to the COVID-19 pandemic. *Public Health Reports, 137*(2), 336–343.
- Levy, N. N. (2021). Covid was a tipping point for telehealth. If some have their way, virtual visits are here to stay. <https://khn.org/news/article/covid-was-a-tipping-point-for-telehealth-if-some-have-their-way-virtual-visits-are-here-to-stay/>
- Lopez, L., 3rd, Hart, L. H., 3rd, & Katz, M. H. (2021). Racial and ethnic health disparities related to COVID-19. *JAMA, 325*(8), 719–720.
- Mitchell, S. M. (2021). True resilience: A look inside COVID's effect on children with medical complexity and their families. *Current Pediatrics Reports, 9*, 171–177.
- Poghosyan, L., Pulcini, J., Chan, G. K., Dunphy, L., Martsolf, G. R., Greco, K., Todd, B. A., Brown, S. C., Fitzgerald, M., McMenamin, A. L., & Solari-Twadell, P. A. (2022). State responses to COVID-19: Potential benefits of continuing full practice authority for primary care nurse practitioners. *Nursing Outlook, 70*(1), 28–35.
- Rosen-Reynoso, M., Porche, M. V., Kwan, N., Bethell, C., Thomas, V., Robertson, J., Hawes, E., Foley, S., & Palfrey, J. (2016). Disparities in access to easy-to-use services for children with special health care needs. *Maternal and Child Health Journal, 20*(5), 1041–1053.
- Schweiberger, K., Patel, S. Y., Mehrotra, A., & Ray, K. N. (2021). Trends in pediatric primary care visits during the coronavirus disease of 2019 pandemic. *Academic Pediatrics, 21*(8), 1426–1433.
- Shankar, L. G., Habich, M., Rosenman, M., Arzu, J., Lales, G., & Hoffmann, J. A. (2022). Mental health emergency department visits by children before and during the COVID-19 pandemic. *Academic Pediatrics, 22*(7), 1127–1132.
- Sillow-Carroll, S., DuPlessis, H., Henry, E., & DiPaola, S. (2021). COVID-19 policy flexibilities affecting children and youth with special health care needs. What to keep, modify or discard? https://www.lpfch.org/sites/default/files/field/publications/covid-19-hma-report_1.pdf
- Vish, N. L., & Stolfi, A. (2020). Relationship of children's emotional and behavioral disorders with health care utilization and missed school. *Academic Pediatrics, 20*(5), 687–695.
- Yu, J. A., McKernan, G., Hagerman, T., Schenker, Y., & Houtrow, A. (2021). Most children with medical complexity do not receive care in well-functioning health care systems. *Hospital Pediatrics, 11*(2), 183–191.
- Yue, D., Pourat, N., Chen, X., Lu, C., Zhou, W., Daniel, M., Hoang, H., Sripipatana, A., & Ponce, N. A. (2019). Enabling services improve access to care, preventive services, and satisfaction among health center patients. *Health Affairs, 38*(9), 1468–1474.