Children With Complex Chronic Conditions in the Child Protective Services

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abstract

OBJECTIVES: Little is known about the prevalence and outcomes for children with complex chronic conditions (CCCs) in the Child Protective Services (CPS) system. We aimed to determine the prevalence and associations of CCC designation across CPS outcomes and years among a group of children reported in CPS.

METHODS: This was a retrospective, cross-sectional study using CPS and Medicaid data among children enrolled in Medicaid in Kentucky and Florida who were reported to CPS January 1, 2017, to December 31, 2020. The primary outcome was a CCC, distinguished with diagnosis codes in Medicaid claims. We derived logistic regression models to assess the aOR of a child having a CCC by type of maltreatment, report substantiation, and foster care placement, after adjusting for covariates.

RESULTS: Among 610 886 children reported to CPS, 8.7% had a CCC. The percentage of children with a CCC increased from 6.2% to 10.7% from 2017 to 2020. A higher percentage of children in foster care vs those who were not had a CCC (18.1% vs 8.3%). Children reported for medical neglect were more likely to have a CCC (aOR, 4.53 [95% CI, 4.32–4.76]) compared with those reported for basic needs neglect. Report substantiation (aOR, 1.21 [95% CI, 1.18–1.24]) and foster care placement (aOR, 1.43 [95% CI, 1.37–1.49]) were both associated with CCC diagnoses.

CONCLUSIONS: Children with CCCs represent a distinct and prevalent group of children reported to CPS and placed into foster care. Multisectoral systems of support are needed for these children and their families prior to and throughout CPS involvement.

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RW Cleveland conceptualized and participated in study design, applied for access to data, assisted in determining analytic approach, interpreted data, and was an author of the manuscript. HT Puls conceptualized and participated in study design, assisted in determining analytic approach, interpreted data, and was an author of the manuscript. H-F Fong and JG Berry assisted in determining analytic approach and offered crucial topic expertise. J Liu and E Weller assisted in determining analytic approach and performed data analysis. All authors provided critical revision of the manuscript and approved the final version.

CONFLICT OF INTEREST DISCLOSURES: The authors have no conflicts of interest relevant to this article to disclose.

WHAT'S KNOWN ON THIS SUBJECT: Children with disabilities are at an increased risk for all-form maltreatment. Children with chronic conditions appear to be at increased risk of medical neglect.

WHAT THIS STUDY ADDS: By applying the Complex Chronic Condition system to a database of linked Medicaid claims and Child Protective Services reports, we show that children with complex chronic conditions are overrepresented in reports, concerns for medical neglect, report substation, and foster care placement.

To cite: Cleveland RW, Fong H-F, Liu J, et al. Children With Complex Chronic Conditions in the Child Protective Services. *Pediatrics.* 2026;158(3):e2025075190

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INTRODUCTION

In order to more clearly categorize children with increased medical needs and measure the associations between medical complexity and health care outcomes, Feudtner et al developed the complex chronic conditions (CCCs) classification system.[1,2] This categorization uses *International Classification of Diseases, 9th/10th Revision* codes derived from payer data, including Medicaid, to identify children with specific diagnoses. CCCs are described as the following: any medical condition that can be reasonably expected to last at least 12 months (unless death intervenes) and to involve either several different organ systems or one organ system severely enough to require specialty pediatric care and probably some period of hospitalization in a tertiary care center.[1]

CCCs include diagnoses such as congenital heart disease, serious neurologic impairment, or chronic renal failure and do not include diagnoses such as diabetes mellitus or asthma. CCCs are a frequently used classification system to identify and study children with medical complexity.[3–5] Leyenaar et al recently found that at least one CCC was prevalent in 11.3% of children.[3]

Children with CCCs have an outsized impact on the medical system. Children with CCCs account for 10% of the US hospital admissions and over 40% of pediatric hospital charges.[6] Children with CCCs also present challenges to parents. Parents of children with special health care needs frequently report financial problems and unmet medical needs related to their child's condition.[7] Not surprisingly, parents of children with CCCs have been shown to have lower health-related quality of life.[8]

The unique and challenging aspects of caring for a child with chronic medical needs potentially put these children at an increased risk for maltreatment.[9,10] Child maltreatment is a heterogenous term including numerous types of abuse and neglect. Concerns for basic needs neglect and medical neglect may arise more often among children with CCCs given the unique medical and psychosocial demands placed on caregivers. Children with CCCs may be at greater risk for physical abuse if the demands on their care exacerbate stress or mental illness among their caregivers. Additionally, when maltreatment concerns arise, complexity, clinical uncertainty, and intensity in a child's medical care needs likely present challenges to Child Protective Services (CPS) and the foster care system.

There is evidence to suggest that children with disabilities are at increased risk for maltreatment as outlined in a statement from the American Academy of Pediatrics.[11] The studies underpinning that statement often investigated intellectual disability, emotional/behavioral disability, or other neurodevelopmental disabilities.[12,13] Other studies have investigated specific medical conditions such as cerebral palsy[14] or Down syndrome.[15] These studies, however, have been narrow in their assessments of "disabilities" and individual conditions and have not adequately assessed the total scope of medical conditions in the context of child maltreatment and CPS outcomes.

To better understand how medical diagnoses, beyond those few described previously, are associated with maltreatment CPS reporting and outcomes, we need to look more broadly at the medical conditions of children reported to CPS. Focusing on CCCs provides one avenue to this end. Children with CCCs have increased contact with the medical community and represent a population unique from the general pediatric population.

In this study, we aimed to determine the prevalence and associations of CCC designation across CPS outcomes and years among a group of children reported to CPS. To achieve this, we used a 2-state, multiyear database of linked CPS and Medicaid claims data. We hypothesized that a child having at least one CCC would be more associated with medical neglect concerns compared to other maltreatment types and that because the population of children with CCCs is increasing,[16] the proportion of children reported to CPS with a CCC would increase over the course of our study.

METHODS

Design, Setting, and Participants

This was a retrospective cross-sectional study of children aged 0 to 17 years reported to the CPS systems in Kentucky and Florida from January 1, 2017, through December 31, 2020, who were enrolled in Medicaid at any point in the study period. Data were obtained from the Child and Caregiver Outcomes Using Linked Data (CCOULD).[17] CCOULD is an administrative data set of children investigated by CPS in Kentucky and Florida whose child protection data were deterministically linked to their Medicaid coding and billing data. CCOULD data are archived at the National Data Archive on Child Abuse and Neglect (NDACAN). Only children's first reports to CPS during the study years were included. The maltreatment types reported in CCOULD are physical abuse, neglect or deprivation of necessities (ie, basic needs neglect), medical neglect, sexual abuse, psychological or emotional maltreatment, no alleged maltreatment, and unknown or missing. Because of their unclear significance, reports with "no maltreatment" alleged, missing, or unknown maltreatment were excluded (n = 329 828). This study followed the Strengthening the Reporting of Observational Studies in Epidemiology reporting guidelines.[18] The institutional review board at the Boston Children's Hospital deemed our study exempt from institutional board review.

Main Outcome Measure

The primary outcome was presence of a CCC. CCCs are defined generally as the following: any medical condition expected to last at least 12 months and involve several

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organ systems or one severely enough to require specialty care and hospitalization.[1] CCCs were distinguished from any diagnosis code level and from any Medicaid encounter with an *International Classification of Diseases, 10th Revision, Clinical Modification* code 12 months prior to 1 month after the first CPS report. Within that study observation window, we recorded the month of first CCC diagnosis coding.

Diagnoses in Medicaid data for both the month of and the month following CPS reports were included to capture CCC diagnoses that could have evaded detection prior to the suspected maltreatment, which can be common.[19] However, this approach also allowed for the inclusion of CCC diagnoses potentially resulting from the alleged maltreatment.

Exposure Variables

The primary exposure was primary maltreatment type from the first maltreatment report as reported in CCOULD including basic needs neglect, medical neglect, physical abuse, sexual abuse, and emotional maltreatment. Secondary CPS exposure variables of interest included year of first CPS report during the study period, substantiation determinations, and foster care placement. Confounding variables included child age at time of first CPS report, state of residence, and sex.

Statistical Analysis

We described the study population's demographic and clinical characteristics, exposures, and outcomes with counts and frequencies. We derived 3 separate logistic regression models to determine the aORs and 95% CIs of a child having a CCC by primary exposure variable of interest: type of maltreatment reported (basic needs neglect reference; model 1), report substantiation (model 2), and foster care placement (model 3). The outcome for each model was any CCC. All 3 models were adjusted for year of maltreatment report, child age at time of first CPS report, state of residence, and sex. The models examining substantiation determinations and foster care placements as exposure variables were additionally adjusted for primary maltreatment type. Analyses were conducted using SAS version 9.4 software (SAS Institute Inc) with a significance threshold of 0.05 (2-sided).

RESULTS

Characteristics of the Study Population

There were 610 886 unique children enrolled in Medicaid in Florida or Kentucky during the study who had a report filed to CPS for suspected maltreatment. The majority of children reported to CPS resided in Florida (67.2%) and—for both states combined—were male (50.1%). The primary maltreatment types were basic needs neglect (73.2%), physical abuse (17.7%), sexual abuse (4.4%), emotional maltreatment (2.9%), and medical neglect (1.8%) (Table 1). Overall, 90 085 (14.8%) children were substantiated as having experienced maltreatment and 22 473 (3.7%) of children were placed in foster care. There was a decrease in total reports in 2020.

Main Outcome Measure: CCCs

Overall, 52 931 (8.7%) of CPS-reported children had a CCC (Table 1). CCCs were most common among children primarily reported to CPS for medical neglect (23.9%), followed by neglect (9.2%) and physical abuse (6.2%). CCCs were most common (40.7%) among infants younger than 1 year of age with a CPS report. The proportion of CPS-reported children with a CCC increased from 6.2% in 2017 to 10.7% in 2020 (Table 1). The proportion of children with a CCC diagnosis increased across the spectrum of CPS involvement: 8.7% of CPS-reported children had a CCC, 11.7% of children with a substantiated report had a CCC, and 18.1% of children placed into foster care had a CCC (Table 1). The majority (62.9%) of children reported to CPS with a CCC had that diagnosis first documented during the 12 months prior to the month of their CPS report (Table 2).

Primary Maltreatment Type and CCC Diagnoses (Model 1)

In multivariable analysis, children reported to CPS for medical neglect vs basic needs neglect were significantly more likely to have a CCC (aOR, 4.53 [95% CI, 4.32–4.76], $P < .01$; Table 3). Children reported for sexual abuse vs basic needs neglect had a lower odds of having a CCC (aOR, 0.84 [95% CI, 0.80–0.89], $P < .01$), and children reported for emotional maltreatment vs basic needs neglect had a lower odds of having a CCC (aOR, 0.78 [95% CI, 0.72–0.84], $P < .01$; Table 3).

In multivariable analysis, children's odds of having a CCC increased significantly (aOR, 1.51 [95% CI, 1.246–1.56], $P < 0.01$) in 2020 compared to 2017 (Table 3).

Infants younger than 1 year of age compared with children aged 12 to 17 years had the greatest odds of having a CCC (aOR, 12.49 [95% CI, 12.14–12.86], $P < 0.01$). There were increased odds of a CCC diagnosis among CPS-reported children in Florida compared to Kentucky (aOR, 2.64 [95% CI, 2.58–2.70], $P < 0.01$) and lower odds of a CCC diagnosis among girls compared to boys (aOR, 0.91 [95% CI, 0.90–0.93], $P < 0.01$).

Substantiation (Model 2), Foster Care Placement (Model 3), and CCC Diagnoses

In multivariate analysis, children's odds of having a CCC were significantly greater if their CPS report was substantiated compared to unsubstantiated (aOR, 1.21 [95% CI, 1.18–1.24], $P < .01$) and if they were placed into foster care compared to not placed (aOR, 1.43 [95% CI, 1.37–1.49],

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TABLE 1. Study Participant Characteristics and Prevalence of CCCs Among CPS-Reported Children

	Total N = 610 886 n(%)	Diagnosis of CCCs	
		No n = 557 955 (91.3%) n (%)	Yes n = 52 931 (8.7%) n (%)
Maltreatment type			
Physical abuse	107 846 (17.7)	101 136 (93.8)	6710 (6.2)
Medical neglect	11 101 (1.8)	8443 (76.1)	2658 (23.9)
Sexual abuse	27 142 (4.4)	25 748 (94.9)	1394 (5.1)
Emotional maltreatment	17 737 (2.9)	16 879 (95.2)	858 (4.8)
Neglect	447 060 (73.2)	405 749 (90.8)	41 311 (9.2)
Substantiation			
Substantiated	90 085 (14.8)	79 558 (88.3)	10 527 (11.7)
Unsubstantiated	520 801 (85.3)	478 397 (91.9)	42 404 (8.1)
Foster care placement			
Yes	22 473 (3.7)	18 404 (81.9)	4069 (18.1)
No	588 413 (96.3)	539 551 (91.7)	48 862 (8.3)
Age, y			
<1	54 178 (8.9)	32 127 (59.3)	22 051 (40.7)
1–4	142 043 (23.3)	130 381 (91.8)	11 662 (8.2)
5–11	242 055 (39.6)	232 869 (96.2)	9186 (3.8)
12–17	172 610 (28.3)	162 578 (94.2)	10 032 (5.8)
Maltreatment report year			
2020	70 592 (11.6)	63 076 (89.4)	7516 (10.7)
2019	130 501 (21.4)	116 545 (89.3)	13 956 (10.7)
2018	171 444 (28.1)	154 708 (90.2)	16 736 (9.8)
2017	238 349 (39.0)	223 626 (93.8)	14 723 (6.2)
State			
Florida	410 399 (67.2)	367 940 (89.7)	42 459 (10.4)
Kentucky	200 487 (32.8)	190 015 (94.8)	10 472 (5.2)
Sex			
Female	304 844 (49.9)	279 758 (91.8)	25 086 (8.2)
Male	306 042 (50.1)	278 197 (90.9)	27 845 (9.1)

Abbreviations: CCC, complex chronic condition; CPS, Child Protective Services.

TABLE 2. Timing Relationship Between First CCC Diagnosis and First CPS Report Within Study Period, n = 52 931

Timing	n (%)
Within 12 mo prior to CPS report	33 285 (62.9)
Month of CPS report	16 929 (32.0)
Month following CPS report	2717 (5.1)

Abbreviations: CCC, complex chronic condition; CPS, Child Protective Services.

$P < 0.01$). The associations between a child having a CCC diagnosis and child age, report year, state, and sex were essentially consistent in both the substantiation model and the foster care model (Table 4) when compared to the measured associations in the primary maltreatment type model (Table 3).

DISCUSSION

These results support 3 important conclusions with potential impact on medical communities, CPS and foster care systems, and public policy, namely, that children with CCCs (1) were particularly prone to medical neglect concerns, (2) appear to be at increased risk for foster care placement, and (3) were prevalent within CPS.

CCCs and Medical Neglect

Children reported for medical neglect had more than 4-fold greater odds of having a CCC, highlighting a potential vulnerability. These children may be subject to surveillance bias given that they have more interactions with the medical system than children without increased medical needs.[20–22] Some concerns for medical neglect may arise from a mismatch of medical expectations and perceptions of a

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TABLE 3. Multivariable Analysis of Maltreatment Type and Diagnosis of CCCs

	aOR	95% CI	*P* Value
Maltreatment type			
Physical abuse	1.01	0.98–1.04	.65
Medical neglect	4.53	4.32–4.76	<.0001
Sexual abuse	0.84	0.80–0.89	<.0001
Emotional maltreatment	0.78	0.72–0.84	<.0001
Neglect	reference		
Age, y			
<1	12.49	12.14–12.86	<.0001
1–4	1.53	1.48–1.57	<.0001
5–11	0.66	0.64–0.68	<.0001
12–17	reference		
Maltreatment report year			
2020	1.51	1.46–1.56	<.0001
2019	1.60	1.56–1.65	<.0001
2018	1.59	1.56–1.63	<.0001
2017	reference		
State			
Florida	2.64	2.58–2.70	<.0001
Kentucky	reference		
Sex			
Female	0.91	0.90–0.93	<.0001
Male	reference		

Abbreviation: CCC, complex chronic condition.

caregiver's ability to meet those expectations.[23] For instance, when a safe, straight-forward, and agreed-upon discharge plan cannot be formulated, health care physicians can struggle with determining the best approach to intervention.[24] Physicians should work to recognize potentially unrealistic expectations of parents and adjust care plans in a manner that respects parents' current goals of care for their children and does not present significant risk for harm, understanding that parents' goals often change as a child's condition progresses.[25] A standardized upstream approach to medical neglect concerns when a child has one or more CCCs may yield more nuanced and consistent outcomes.

Logistically, as greater demands are placed on parents, as with children with CCCs, it can become increasingly difficult for parents to meet them.[7] Shortfalls in government assistance, community support, and availability of home health care may impact the quantity and quality of care that these children receive at home.[26] There is an understanding of the link across social determinants of health, poverty, and neglect concerns.[27] This highlights the need for increased upstream medical and concrete supports for parents of children with CCCs in order to optimize medical outcomes and reduce the need for CPS involvement and foster care.

CCCs and Foster Care

Nearly 1 in 5 children placed into foster care during our study had a CCC. Poor health status of children at entry to foster care is well documented,[19] and our study adds context that CCCs, specifically, are also prevalent. Although we are unable to assess how CCCs may contribute to CPS involvement and outcomes, others have estimated that 5% to 10% of the foster care population are in foster care due to medical complexity.[28] Additionally, medical complexity is associated with poorer outcomes following foster care.[29] This highlights a critical need to improve upon current supports for children with medical needs in foster care through improved health care management and health care financing.[30]

The goal of the foster care system is to ensure the continued wellness of children should their home environment be deemed unsafe.[31] Challenges relating to health care management represent barriers to this goal. Children with CCCs are often followed closely by multiple medical specialists whose follow-up must be ensured, who are on medications that need to be administered correctly and refilled on time, and who are potentially prone to medical status changes that must be recognized and acted upon in a timely manner. Significant barriers exist in carrying forward the medical histories of children with CCCs through foster care placement, including establishing a new medical home.[32] Emblematic of these challenges, foster parents often report feeling unprepared to take care of children with medical needs.[33] Unique systems of care and greater financial resources are likely required to better support children with CCCs within the foster care system. A medical home—which is legally required for all children in foster care, improves health outcomes, and may reduce health care expenditures—may be especially critical for this population.[19,34,35]

Prevalence of CCCs

The high prevalence of CCC diagnoses among children reported to CPS suggests there is an urgent need to develop multisectoral strategies to adequately assess and support children with unique medical needs as they appear to be at increased risk.

Societally, poverty is strongly linked to concerns for maltreatment, particularly neglect.[27] The logistic and economic burdens associated with providing care for children with CCCs may compound poverty's influence on creating maltreatment risk or perceptions of risk. Addressing inequities in wealth and exogenous economic supports may ease the uneven burden that disproportionately places some families caring for children with CCCs at greater risk for maltreatment. Our study was only able to focus on those children already reported to CPS. Future studies should focus on the population of children with CCCs as a whole to determine risk factors for CPS involvement.

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TABLE 4. Multivariable Analysis of Substantiation and Diagnosis of CCCs, Foster Care Placement, and Diagnosis of CCCs, Considering Separately CPS Substantiation and Foster Care Placement

	Model for CPS Substantiation			Model for Foster Care Placement		
	aOR	95% CI	*P* Value	aOR	95% CI	*P* Value
Maltreatment type						
Physical abuse	1.02	0.99–1.05	0.26	1.01	0.98–1.04	0.37
Medical neglect	4.52	4.30–4.75	<.0001	4.57	4.35–4.80	<.0001
Sexual abuse	0.83	0.78–0.87	<.0001	0.85	0.80–0.90	<.0001
Emotional maltreatment	0.79	0.74–0.85	<.0001	0.79	0.73–0.85	<.0001
Neglect	reference			reference		
Substantiation						
Substantiated	1.21	1.18–1.24	<.0001	not applicable		
Unsubstantiated	reference			not applicable		
Foster care placement						
Yes	not applicable			1.43	1.37–1.49	<.0001
No	not applicable			reference		
Age, y						
<1	12.17	11.82–12.53	<.0001	12.17	11.82–12.53	<.0001
1–4	1.52	1.47–1.56	<.0001	1.52	1.47–1.56	<.0001
5–11	0.66	0.64–0.68	<.0001	0.66	0.64–0.68	<.0001
12–17	reference			reference		
Maltreatment report year						
2020	1.51	1.47–1.56	<.0001	1.51	1.46–1.56	<.0001
2019	1.61	1.57–1.66	<.0001	1.61	1.57–1.65	<.0001
2018	1.60	1.56–1.64	<.0001	1.60	1.56–1.64	<.0001
2017	reference			reference		
State						
Florida	2.69	2.62–2.75	<.0001	2.62	2.56–2.69	<.0001
Kentucky	reference			reference		
Sex						
Female	0.91	0.90–0.93	<.0001	0.91	0.90–0.93	<.0001
Male	reference			reference		

Abbreviations: CCC, complex chronic condition; CPS, Child Protective Services.

For children with CCCs, medical communities have opportunities to improve practice and improve overall care. Physicians caring for children with CCCs are likely to interact with CPS. Our findings suggest a need for development of systems of care for children with CCCs to better support children and families before, during, and following CPS report.

The CPS system was originally conceived to ensure children's safety from physical violence.[36] Most maltreatment reports are related to physical abuse, basic needs neglect, and/or sexual abuse.[37] Frontline CPS workers may not be sufficiently prepared to assess and address maltreatment concerns in the context of complex or multiple medical diagnoses. Systems-based solutions may provide opportunities to overcome individual-level barriers. Ideally, CPS would be able to identify children with CCCs at the time of report intake, accurately gauge the degree of medical complexity present, and use this information when making substantiation determinations and safety plans. This could be accomplished by standardizing identification of children with CCCs, by creating and using specialized CPS teams for those children, and by establishing more robust systems for bidirectional communication with children's medical teams.

This study has a few important limitations. The first is generalizability. Florida and Kentucky may not be representative of other states, and there are likely differences in reporting practices between the 2 states. Additionally, our database only included children enrolled in Medicaid; the inferences made from these data may not extend to children covered by other insurance types. Second, the nature of our data and design do not allow for causal inferences. Third is our decision to focus on children with one or more

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CCCs. Children with CCCs are a heterogenous group and may not entirely represent the spectrum of children with increased and complex health care needs. Still, even a single CCC differentiates a child from a typically developing one based upon their increased involvement with the medical community and demands on their caregivers. Additionally, children with a CCC and a report to CPS represent a population with both elevated medical needs and social complexity. Further examination of degree of medical complexity and intersection with CPS deserves future study.

Fourth, several factors influencing reporting decisions and calculations of risks/benefits of those reports were unmeasured in this study, and these factors deserve future study.

Fifth, the CCOULD database lacked valid race and ethnicity data. Hence, we were unable to determine associations between a child having a CCC and CPS outcomes in the context of race and ethnicity. Finally, because the goal was to report on prevalence of CCCs in a cohort of CPS-involved children, we included CCCs diagnosed during the month of and month following CPS reports. It is possible, therefore, that some CCCs were a result of abuse/neglect and were not preexisting. Regardless, CCCs are expected to last at least 12 months, which would have importance for children, CPS, and the foster care system, whether they were preexisting or new. Despite these limitations, this study is one of the first and largest to examine the relationships between presence of complex medical diagnoses and CPS outcomes.

CONCLUSION

Taken together, our findings suggest that children with CCCs are a unique and prevalent group within the population of children reported to CPS and in the foster care system. The medical community, CPS, and the foster care system need to strengthen their processes and cross-sectoral collaborations to support this unique population of children and their families both to mitigate the need for CPS involvement and throughout CPS involvement.

ACKNOWLEDGMENTS

The data used in this publication were made available by the National Data Archive on Child Abuse and Neglect (NDACAN) and have been used with permission. Data from the Child and Caregiver Outcomes Using Linked Data (CCOULD) were originally provided by the project team at RTI International, including Tami Mark, Melissa Dolan, Benjamin Allaire, Keith Smith, Will Parish, Christina Bradley, and Claire Strack, as well as Emily Madden at the Office of the Assistant Secretary for Planning and Evaluation (ASPE) and Valeria Butler at the Administration for Children and Families. Funding for the project was provided by the Patient-Centered Outcomes Research Trust Fund (PCORTF) from SSF1 (award number: HHSP233201500039I). The analyses presented in this publication were based on data from CCOULD. These data were provided by the NDCAN and have been used with permission. The data were originally collected under the auspices of the Kentucky Cabinet for Health and Family Services, Department for Community Based Services and the Kentucky Cabinet for Health and Family Services, Department for Medicaid Services. Funding was provided by ASPE and PCORTF. The collector of the original data, the funder, NDACAN, Duke University, Cornell University, and the agents or employees of these institutions bear no responsibility for the analyses or interpretations presented here. The information and opinions expressed reflect solely the opinions of the authors and should not be construed as representing the opinions or policy of the US Department of Health and Human Services.

ABBREVIATIONS

CCC: complex chronic condition
CPS: Child Protective Services
CCOULD: Child and Caregiver Outcomes Using Linked Data
NDACAN: National Data Archive on Child Abuse and Neglect

FUNDING: H Fong is supported in part by the National Institutes of Health (K23MD016171). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Accepted for Publication Date: May 13, 2026

https://doi.org/10.1542/peds.2025-075190

COMPANION PAPER: A companion to this article can be found online at www.pediatrics.org/cgi/doi/10.1542/peds.2026-077262.

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