



Medical complexity and placement outcomes for children in foster care

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ABSTRACT

Objective: Medical complexity threatens placement stability and permanency outcomes for children in foster care (FC). This study aimed to characterize for US children in FC: 1) medical complexity, using number of diagnosed types of disability as a proxy; 2) demographic and removal characteristics based on level of complexity; and 3) whether increasing levels of complexity were associated with foster care placement outcomes.

Methods: The analysis included children in FC, ages 0–21 whose disability status was clinically assessed and documented ($n = 538,695$). Using data from the FY 2014 Adoption and Foster Care Analysis and Reporting System, medical complexity was categorized (0–4+) based on 5 disability types: emotional, hearing/vision, intellectual, physical, and other. Bivariate analyses (χ^2 tests, Kruskal-Wallis) compared the distribution of demographic and removal characteristics among complexity groups. Multiple logistic regression evaluated relationships between medical complexity and placement outcomes, including length of stay in FC, placement stability, and permanency.

Results: Twenty-three percent of the sample had 1 disability type, 7% had 2, 3% had 3, 1% had 4+, and 67% had no disability. Children with increasing complexity were more likely to be older, older on FC entry, male, Black, non-Hispanic, placed in a group home or institution, have abuse, neglect, and/or child disability/behavior as reason for removal, and have poor placement outcomes.

Conclusion: Children in FC with greater medical complexity are at risk for undesirable placement outcomes. By recognizing and addressing the unique needs of this vulnerable population, pediatric providers and child welfare staff may identify strategies to improve placement outcomes.

1. Introduction

On any given day in the United States, nearly 430,000 children are in foster care (Children's Bureau, 2016b) and many have been exposed to social risk factors that influence pediatric health disparities, including poverty, single parent homes, maternal mental health concerns, minority race/ethnicity, and violence (Larson, Russ, Crall, & Halfon, 2008; Stein, Siegel, & Bauman, 2010). Children in foster care utilize a disproportionate amount of health services (Becker, Jordan, & Larsen, 2006; Jee & Simms, 2006; Knight, McDuffie, Gifford, & Zorc, 2016). The American Academy of Pediatrics (AAP) classifies children in foster care as a population of children with special health care needs (CSHCN) based on their high prevalence of health problems and unmet health-care needs (Szilagyi, Rosen, Rubin, et al., 2015).

CSHCN is a broad definition that includes children “who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (McPherson, Arango, Fox, et al., 1998). Within the broader category of CSHCN is a subgroup of children known as children with medical complexity (CMC), who have the most intensive health care needs and are particularly fragile (Cohen, Kuo, Agrawal, et al., 2011). Cohen et al. defines CMC based on 4 domains—substantial health care service needs, at least 1 chronic condition that is severe and/or associated with medical fragility, functional limitations, and high health care utilization (Cohen et al., 2011). The population of CMC is growing, in part due to advances in neonatal and critical care medicine, technology, and nutrition (Burns et al., 2010). For some CMC, their

Abbreviations: AAP, American Academy of Pediatrics; CSHCN, Children with Special Health Care Needs; CMC, Children with Medical Complexity; US, United States; LOS, Length of Stay; AFCARS, Adoption and Foster Care Analysis and Reporting System; DHHS, Department of Health and Human Services; SSI, Supplemental Security Income; IEP, Individualized Education Plan

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biological parents are unable to provide the intensive level of care required and they enter the child welfare system (Seltzer, Henderson, & Boss, 2016).

Child welfare agencies provide services to oversee safe placements, and strive to achieve safety, well-being, stability, and permanency for every child in foster care (Children's Bureau; Children's Bureau, 2012a). Placement stability, defined by the Department of Health and Human Services (DHHS) as 2 or fewer different placements within a foster care removal period (Children's Bureau, 2016a), is an important outcome in child welfare. Placement stability supports development of attachments with caregivers and reduces child stress and behavioral and academic achievement problems (Carnochan, Moore, & Austin, 2013). In contrast, placement instability is associated with attachment disorders and behavior problems (Carnochan et al., 2013; Rubin, O'Reilly, Luan, & Localio, 2007), creating additional barriers to successful placements. Placement instability can exacerbate existing behavioral problems and lead to new behavior problems (Carnochan et al., 2013; Newton, Litrownik, & Landsverk, 2000; Rubin et al., 2007). One study found that children who failed to achieve placement stability, compared to those who achieved stability in foster care, had a 36–63% increased risk of behavioral problems (Rubin et al., 2007). Former foster youth describe placement moves as experiences of profound loss and resultant challenges with trusting others and managing interpersonal relationships (Unrau, Seita, & Putney, 2008).

To facilitate permanent placements, child welfare teams establish plans for achieving case goals; the preferred and most common goal is reunification with the child's biological parent(s). When reunification is not feasible, the goal is to place the child in another legally permanent family—with relatives, through adoption, or through guardianship (Children's Bureau). In 2014, over 20,000 children “aged out” of the foster care system without ever achieving permanency (Children's Bureau, 2015).

CMC in foster care are a particularly vulnerable population due to their concurrent medical risks and social risks, a combination shown to result in higher healthcare utilization and poorer health outcomes than either risk alone (Stein et al., 2010). Yet, very little is known about this population. Thirty percent of children in foster care have at least 1 chronic condition (Jee et al., 2006; Szilagyi et al., 2015), but existing child welfare databases do not typically collect the level of health information needed to categorize children in foster care by level of medical complexity. As such, systematic data about child welfare and health outcomes for CMC in foster care are lacking because this group of children is not readily identifiable (Williams, Seltzer, & Boss, 2017).

Existing databases do report disability status and prior studies have shown that having a disability is a barrier to permanency and associated with other poor outcomes (Children's Bureau, 2016a; Hill, 2012; Lockwood, Friedman, & Christian, 2015; Slayter, 2016a; Slayter, 2016b). Children with disabilities experience higher rates of maltreatment and are disproportionately represented in the child welfare system (Lightfoot, 2014). Studies have shown that foster youth with disabilities, compared to those without disabilities, have longer lengths of stay in foster care, are less likely to be reunified with their parents or achieve permanency, have higher rates of placement and adoption disruptions, perform worse academically, and receive lesser quality services (Geenen & Powers, 2006; Hill, 2012; Lightfoot, 2014; Romney, Litrownik, Newton, & Lau, 2006; Slayter, 2016a; Steen & Harlow, 2012). In 2013, only 79% of children with a diagnosed disability achieved permanency when exiting foster care, compared to 89% of all children exiting foster care (Children's Bureau, 2016a). Yet, simply reporting presence or absence of disability does not provide meaningful information regarding the severity or complexity of a child's health problems, which may differentially impact placement and permanency.

Better understanding how medical complexity relates to child welfare outcomes could allow health care providers and other professionals working with children in foster care to identify a population at risk for poor outcomes and target resources and strategies to better address

their unique needs. The objectives of this study were to characterize for US children in foster care: 1) medical complexity, using number of diagnosed types of disability as a proxy; 2) demographic and removal characteristics based on level of complexity; and 3) whether increasing levels of complexity were associated with foster care placement outcomes, including length of stay (LOS) in foster care, placement stability, and permanency.

2. Methods

2.1. Study design and data source

A secondary analysis of data from the Fiscal Year 2014 Adoption and Foster Care Analysis and Reporting System (AFCARS) Foster Care File was conducted (Children's Bureau, 2014). AFCARS, a federally mandated reporting system, collects case-level information on every child served by state or tribal Title IV-E agencies that provide adoption or foster care services (Children's Bureau, 2017). The Children's Bureau, DHHS, oversees AFCARS. Data were de-identified and publically available through the National Data Archive on Child Abuse and Neglect (Children's Bureau, 2014). The Johns Hopkins Institutional Review Board approved this study. Individuals in the AFCARS database were included if they were 21 years of age or younger, and their disability status was clinically assessed and documented.

2.2. Measures

2.2.1. Primary independent variable: Medical complexity score

AFCARS codes for 5 different disability types but does not have specific variables for medical complexity. The primary independent variable, medical complexity score, was derived from the disability coding. Medical complexity was categorized from 0 to 4+ (no diagnosed disability to most complex) based on the number of 5 disability types coded in the database: emotional, visual/hearing, intellectual, physical, and other (Table 1).

While disability and medical complexity are not equivalent terms, they have many overlapping features; disability is the closest proxy to medical complexity available in AFCARS. The Americans with Disabilities Act states that an individual with a disability “is a person who has a physical or mental impairment that substantially limits one or more major life activities” (US Department of Justice, 2009). The terminology used to define disabilities in AFCARS (Table 1) includes functional limitations, chronicity, and severity, which overlaps with Cohen's domains of medical complexity (Cohen et al., 2011). While not specifically included in the definitions, the two other domains for medical complexity—higher healthcare utilization and service needs—relate to children in foster care in general (Becker et al., 2006; Jee & Simms, 2006; Knight et al., 2016), but likely are even more pronounced for children with disabilities.

State welfare agencies report whether a qualified professional has clinically assessed the child and diagnosed a disability. Agencies are instructed to code all diagnosed disability types for each child in their care. “Not yet determined” for clinical disability indicates that a clinical assessment has not yet been conducted. Only children who were clinically assessed were included in this analysis.

2.2.2. Dependent variables: Placement outcomes

Placement outcomes included LOS in foster care, placement stability, and permanency case goal. DHHS outcome measure definitions for extended length of stay (> 24 months) and placement stability (2 or fewer placement settings within a single foster care removal period) were used for this analysis (Children's Bureau, 2016a). LOS in foster care (in days) was converted to a binary outcome with a cut-point of 24 months (730 days). For this analysis, number of placement settings was dichotomized to 2 or fewer vs. > 2 placements (instability). Based on AFCARS guidelines, trial home visits are not counted towards

Table 1
AFCARS codebook definitions of disability types^a.

Disability type	AFCARS definition	Examples (not all inclusive)
Emotional	A condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree: An inability to build or maintain satisfactory interpersonal relationships; inappropriate types of behavior or feelings under normal circumstances; a general pervasive mood of unhappiness or depression; or a tendency to develop physical symptoms or fears associated with personal problems. Does not include social maladjustment, unless also seriously emotionally disturbed.	ADHD, mood disorders, anxiety, autism, schizophrenia, eating disorders, reactive attachment disorder
Vision/hearing	Visual or hearing impairment that may significantly affect educational performance or development	Blindness, cataracts, glaucoma, retinal detachment, hearing loss
Intellectual	Significantly below average general cognitive and motor functioning existing concurrently with deficits in adaptive behavior manifested during the developmental period that adversely affect socialization and learning	Trisomy 21, hydrocephalus, microcephaly, borderline cognitive functioning, intellectual disability (all degrees)
Physical	Physical condition that adversely affects day-to-day motor functioning	Cerebral Palsy, spina bifida, multiple sclerosis, orthopedic impairments
Other	Conditions other than those noted above which require special medical care, such as chronic illnesses.	Cancer, diabetes, epilepsy, congenital heart disease, sickle cell anemia

Available at: http://www.ndacan.cornell.edu/datasets/pdfs_user_guides/AFCARSFosterCareCodebook.pdf

^a Definitions and examples were taken from: National Data Archive on Child Abuse and Neglect. "AFCARS Foster Care File CodeBook." Revised 2/1/2016.

number of placements (National Data Archive on Child Abuse and Neglect, 2016).

Case goal plans, which are goals established for each child by the child welfare team, include reunification with parent, adoption, living with a relative, long-term foster care, guardianship, emancipation, or not yet determined. This categorical variable was dichotomized to assess whether children had permanency (reunification, adoption, live with relative, guardianship) or non-permanency goals (long-term foster care, emancipation). "Not yet determined," comprising 5% of the data, was considered missing.

2.2.3. Demographic and removal characteristics

Demographic variables included age, age at foster care entry, sex, race, ethnicity, placement setting, and eligibility and/or receipt of Supplemental Security Income (SSI) and Medicaid benefits. Age was defined as age on the last date of the fiscal year. Age at entry (years) was derived by calculating the number of days between birth date and first removal date. Race was coded as: White, Black, American Indian/Alaskan Native, Asian, Hawaiian/Pacific Islander, or more than one race. Race coded in the dataset as "unable to determine", was considered missing. Ethnicity was coded as Hispanic or non-Hispanic. Hispanic was defined in the codebook as "child is of Mexican, Puerto Rican, Cuban, Central or South American origin, or a person of other Spanish cultural origin." (National Data Archive on Child Abuse and Neglect, 2016) Ethnicity coded in the dataset as "not applicable" or "unable to determine" was considered missing. Current placement settings included non-relative and relative foster family homes, pre-adoption homes (family intends to adopt), trial home (returned to principal caretaker for trial period), group home (24-hour care in small group setting), institution (24-hour care and/or treatment facility), supervised independent living (under supervision of the agency without 24-hour adult supervision), and runaway (National Data Archive on Child Abuse and Neglect, 2016).

Removal characteristics relate to the manner (voluntary vs. court ordered) in which children were removed from their caregiver and reason(s) for removal (neglect, abuse, parental substance use, child substance use, child disability, child behavior, parental illness/disability, parental incarceration, parental death, housing, abandonment/relinquishment). In this analysis, sexual and physical abuse were combined as "abuse" and alcohol and drug use were combined as "substance use." In the database, each reason for removal is coded separately as yes/no, and a child can have multiple reasons for removal.

2.3. Statistical analysis

Bivariate analyses, including χ^2 tests for categorical variables and Kruskal-Wallis tests for continuous variables, compared the distribution of demographic and removal characteristics among the complexity score groups. Nonparametric tests for trend were performed for ordered categorical variables.

Multiple logistic regression evaluated relationships between complexity score and placement outcomes, including extended LOS in foster care, placement instability, and non-permanency goals. Regression models adjusted for age, age at entry, sex, race, ethnicity, and reasons for removal, based on prior research showing the impact of such characteristics on the specified outcomes (Children's Bureau, 2016a; Children's Bureau, 2016c; Kemp & Bodonyi, 2002; Lightfoot & DeZelar, 2016; Shaw, Bright, & Sharpe, 2015; Vanderploeg et al., 2007). Stratified analysis to evaluate the relationships of interests separately in youth ages 0–17 and ages 18–21 showed that the relationships were similar by age; therefore, the models reported here include youth 0–21. With the exception of race (9% missing), ethnicity (8% missing), and the permanency derived variable (9% missing), the remainder of the variables and derived variables used in this analysis all had < 5% missing data. Due to large sample size and overall low percentage of missingness, observations with missing data were case-wise deleted from analysis.

Collinearity among covariates was evaluated using variance inflation factors and there were no significant findings. Goodness of fit testing with Hosmer-Lemeshow tests ($p < 0.001$) indicated overdispersion, so dispersion correction was used to optimize model fit. Reported adjusted odds ratios (ORs) reflect the dispersion correction. STATA 14 was used for analysis (Stata Statistical Software, 2015).

3. Results

Of the 653,361 children who received foster care services in FY 2014, 538,695 were included in the analysis (Fig. 1). Children who were clinically assessed for disabilities, as opposed to those not yet assessed, were older [8.5(SD 5.9) vs. 7.8(SD 5.9) years], less likely to be Black (26.4% vs. 28.2%), and more likely to be Hispanic (24.1% vs 14.4%, all $p < 0.0001$). There was no difference in gender. Of the top removal reasons, those assessed were more likely to have neglect (62.4% vs 58.0%) and parental illness/disability (17.7% vs 13.7%) as reason for removal, and less likely to have parental substance use

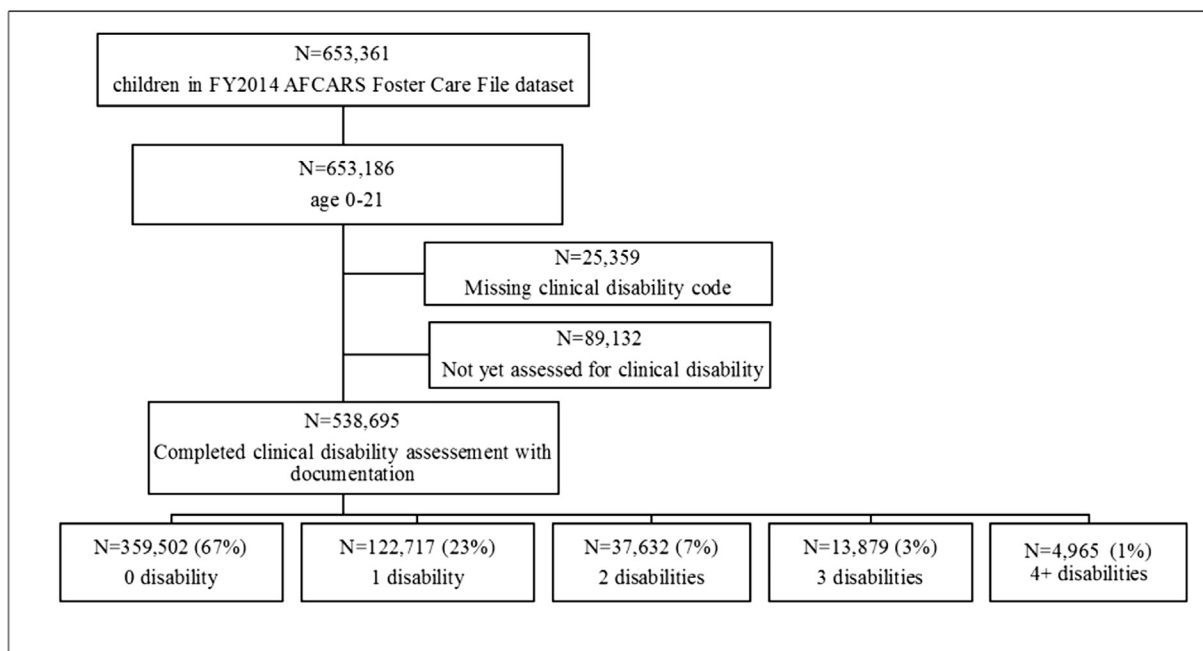


Fig. 1. Sample identification

(31.4% vs 39.5%, all $p < 0.0001$). There was no difference in rates of abuse.

Nineteen percent had an emotional disability, 18% had “other” disability, 7% had a visual/hearing impairment, 3% had an intellectual disability, and 1% had a physical disability. Twenty-three percent of the sample had 1 disability type, 7% had 2, 3% had 3, 1% had 4+, and 67% had no disability (Fig. 1).

In bivariate comparisons, complexity was significantly different by all child characteristics evaluated ($p < 0.0001$) (Table 2). With increasing level of complexity, children were more likely to be older, older on foster care entry, male, Black, and less likely to be White or Hispanic. With increasing complexity, they were also more likely to be receiving SSI and Medicaid, and placed in a group home or institution versus another placement setting (all $p < 0.0001$).

Table 3 shows the relationship between complexity and removal characteristics. Removal manner varied with level of complexity, but without a clear trend. Children with increasing level of complexity were more likely to have neglect, abuse, child disability, and child behavior as reason for removal. With increasing complexity, children were less likely to have the following parental factors as reason for removal: substance use, illness/disability, housing, incarceration, abandonment, and death (all $p < 0.0001$).

There was a direct relationship between LOS (in days) and level of complexity and between number of placements and level of complexity (Table 2). For every additional level of complexity, the proportion of children with each of 3 unfavorable outcomes: extended LOS, placement instability, and non-permanency plan also increased (Table 4). For children without disability compared to children with 4+ disability types, 24.3% versus 76.5% were in care for > 24 months, 28% versus 63.6% had > 2 placement settings, and 5.4% versus 36.4% had a non-permanency plan.

Multiple logistic regression analysis for the 3 outcomes (i.e., LOS, placement instability, and non-permanency) revealed increased odds of poor child welfare outcomes with increasing level of complexity (Table 4). Compared to children with no disabilities, children with the highest complexity score (4+) were 3.2 times more likely to be in foster care for an extended LOS (aOR 3.2, 95% CI [2.9–3.5]), 2.4 times more likely to have placement instability (aOR 2.4, 95% CI [2.2–2.6]), and 5.3 times more likely to have a non-permanency case goal (aOR

5.3, 95% CI [5.0–5.7]), after accounting for demographic and removal characteristics.

4. Discussion

This study characterized children in foster care based on varying levels of medical complexity, as defined by number of disability types, and determined that complexity influenced placement outcomes. While it has previously been reported that having a disability is a barrier to reaching permanency (Hill, 2012; Lockwood et al., 2015; Slayter, 2016b), this is the first study to assess whether varying levels of complexity are differentially related to placement outcomes.

With 1 in 3 children in this sample having at least 1 diagnosed disability, this analysis has relevance to a large population of children in foster care. While additional studies have reported rates as high as 50–87% of children entering foster care with at least 1 medical problem (Leslie et al., 2005; Steele & Buchi, 2008), those rates include acute and less severe chronic problems. For example, asthma is a common chronic condition of childhood, but is not listed as one of the diagnoses in the “other” category of disabilities. Our study aimed to capture the serious chronic conditions that contribute to medical complexity and qualify as a disability based on severity and functional limitations, as opposed to all acute and chronic health problems of children in foster care.

This study demonstrated a direct relationship between level of medical complexity and odds of poor outcomes in foster care, including extended LOS, placement instability, and lack of permanency. While children with any number of disabilities fare worse than children with none, among children with disability, the risk of poor outcomes increased with number of disability types.

Prior research describes additional risk factors that are negatively associated with permanency and stability, including extended time in foster care (> 24 months), older age, entering care at > 12 years, being African American or Native American, being non-Hispanic, being male, and entering care due to parental death, parental substance use, parental illness/disability, or incarceration (Children’s Bureau, 2016a; Children’s Bureau, 2016c; Kemp & Bodonyi, 2002; Lightfoot & DeZelar, 2016; Shaw et al., 2015; Vanderploeg et al., 2007). In this study, children with increasing complexity score were more likely to be older, older at entry, male, and Black—characteristics that have been shown

Table 2
Demographic and placement characteristics by medical complexity, FY2014^a.

Characteristic ^b	Medical complexity score ^c					Total assessed (n = 538,695)
	0 (n = 359,502)	1 (n = 122,717)	2 (n = 37,632)	3 (n = 13,879)	4 + (n = 4965)	
Age, mean(SD), years	7.5(5.7)	10.1(5.9)	11.5(5.5)	11.8(5.8)	12.0(5.7)	8.5(5.9)
Age at entry, mean(SD), years	5.4(5.2)	6.6(5.4)	6.8(5.2)	6.8(5.3)	6.1(5.3)	5.8(5.3)
Male, n (%)	180,959(50.3)	67,112(54.7)	21,419(56.9)	7644(55.1)	2970(59.8)	280,104(52)
Race, n (%)						
White	210,686(63.1)	63,110(59.4)	18,918(56.9)	6950(53.1)	2297(47.3)	301,961(61.5)
Black/AA	81,011(24.3)	30,062(28.3)	10,776(32.4)	5233(40.0)	2342(48.2)	129,424(26.4)
American Indian	10,674(3.2)	2866(2.7)	760(2.3)	155(1.2)	25(0.5)	14,480(3.0)
Asian	2236(0.7)	865(0.8)	223(0.7)	56(0.4)	10(0.2)	3390(0.7)
Hawaiian/PI	960(0.3)	305(0.3)	50(0.2)	15(0.1)	4(0.1)	1334(0.3)
Multi-racial	28,035(8.4)	9052(8.5)	2495(7.5)	682(5.2)	181(3.7)	40,445(8.2)
Hispanic, n(%)	77,120(23.0)	31,423(27.7)	8825(26.5)	2127(18.9)	427(10.9)	119,922(24.1)
Current placement, n (%)						
Non-relative FH	137,218(38.4)	47,251(38.7)	13,845(37)	4735(34.3)	1803(36.4)	204,852(38.2)
Relative FH	107,629(30.1)	25,581(21)	7048(18.8)	2519(18.2)	698(14.1)	143,475(26.8)
Pre-adoptive home	29,015(8.1)	12,509(10.2)	3537(9.4)	1215(8.8)	538(10.9)	46,814(8.7)
Group home	14,224(4)	9,192(7.5)	3506(9.4)	1052(7.6)	232(4.7)	28,206(5.3)
Institution	18,511(5.2)	13,008(10.7)	4686(12.5)	1820(13.2)	805(16.3)	38,830(7.2)
Trial home	44,166(12.4)	9754(8)	2684(7.2)	1110(8)	329(6.6)	58,043(10.8)
Supervised ind.	3426(1)	2508(2)	1216(3.2)	1018(7.4)	454(9.2)	8622(1.6)
Runaway	3,122(0.9)	2248(1.8)	899(2.4)	347(2.5)	92(1.9)	6708(1.2)
Number of placements, mean (SD)	2.4(2.8)	3.5(4.1)	4.3(4.7)	5.1(5.6)	6.0(6.9)	2.9(3.5)
LOS in foster care, mean (SD), days	555.4(629.2)	917.9(948.3)	1272.1(1215.9)	1505(1322.2)	1914.8(1564.2)	720.1(842.7)
SSI recipient, n (%)	14,685(4.1)	10,248(8.4)	4562(12.1)	1889(13.6)	1018(20.5)	32,402(6.0)
Medicaid, n(%)	281,579(78.3)	99,659(81.3)	30,913(82.2)	12,562(90.5)	4767(96)	429,480(79.8)

FH = Foster home; Supervised Ind. = Supervised Independent Living; LOS = Length of Stay; SSI = Supplemental Security Income.

^a The AFCARS 2014 fiscal year extended from October 1, 2013 through September 30, 2014.

^b Missingness for baseline characteristics ranged from 0 to 9%.

^c $p < 0.0001$ for all bivariate analyses (Medical Complexity score versus Characteristic) using X^2 test for categorical characteristics and Kruskal-Wallis for continuous characteristics. $p < 0.0001$ using NP trend for age, age at entry, number of placements, and length of stay in foster care across complexity score groups.

to negatively impact permanency. Relationships between medical complexity and poor outcomes persisted even after adjusting for such demographic and removal characteristics that have been shown to independently effect placement outcomes.

The racial and ethnic disparities that were observed in this study are consistent with findings from the National Survey of Children's Health, which showed that the prevalence of special health care needs was

highest for non-Hispanic Black (24.6%) and White (19.6%) children, while Hispanic (17.6%) children had one of the lowest rates ([Child and Adolescent Health Measurement Initiative, 2017](#)). As black children are disproportionately represented in the child welfare system ([Children's Bureau, 2016c](#)) and the population of children with increasing medical complexity, there is further work to be done to better understand how the intersections of child welfare and health systems can better address

Table 3
Removal characteristics by medical complexity.

Characteristic ^a	Medical complexity score ^b					Total assessed (n = 538,695)
	0 (n = 359,502)	1 (n = 122,717)	2 (n = 37,632)	3 (n = 13,879)	4 + (n = 4965)	
Removal manner, n (%)						
Voluntary	8961 (2.5)	5383 (4.4)	1734 (4.6)	395 (2.8)	63 (1.3)	16,536 (3.1)
Court-ordered	345,724(96.6)	115,831(94.9)	35,543(94.9)	13,422(96.9)	4890(98.7)	515,410 (96.9)
Removal reason(s) ^c , n (%)						
Parental factors						
Neglect	222,449(62.2)	74,704(61.2)	23,918(64)	9604(69.4)	3645(73.5)	334,320 (62.4)
Abuse	62,620(17.5)	22,257(18.2)	6955(18.6)	2659(19.2)	926(18.7)	95,417 (17.8)
Substance use	131,229(36.7)	29,513(24.2)	6217(16.6)	1262(9.1)	223(4.5)	168,444 (31.4)
Illness/disability	60,422(16.9)	24,582(20.2)	7679(20.6)	1719(12.4)	253(5.1)	94,655 (17.7)
Housing	42,011(11.7)	10,850(8.9)	2874(7.7)	677(4.9)	98(2)	56,510 (10.5)
Incarceration	30,025(8.4)	6527(5.4)	1490(4)	282(2)	37(0.8)	38,362 (7.2)
Relinq/abandon	21,181(5.9)	7574(6.2)	2000(5.4)	460(3.3)	98(2)	31,313 (5.8)
Death	5662(1.6)	1435(1.2)	351(0.9)	79(0.6)	25(0.5)	7552 (1.4)
Child factors						
Disability	1501(0.4)	6720(5.5)	2512(6.7)	934(6.8)	257(5.2)	11,924 (2.2)
Behavior	29,944(8.4)	21,925(18)	6537(17.5)	1860(13.4)	372(7.5)	60,638 (11.3)
Substance use	6,952(1.9)	5084(4.2)	783(2.1)	193(1.4)	29(0.6)	13,041 (2.4)

^a Missingness for removal characteristics ranged from 0.5–1.3%.

^b $p < 0.0001$ for all bivariate analyses (Medical Complexity score versus Removal Characteristic) using X^2 test.

^c Individual child can have multiple reasons for removal.

Table 4
Placement outcomes and associations with medical complexity.

Placement outcome ^a	Medical complexity score				
	0	1	2	3	4 +
Extended LOS^b					
In care > 24 months, <i>n</i> (%)	84,205(24.3)	49,730(43.8)	19,967(58.1)	8726(61.1)	3639(76.5)
Unadjusted OR (95% CI)	1.0 [ref]	2.4 (2.4–2.5)	4.3 (4.2–4.4)	6.3 (6.1–6.6)	10.1 (9.5–10.8)
Adjusted ^c OR (95% CI)	1.0 [ref]	1.6 (1.6–1.6)	2.0 (1.9–2.1)	2.6 (2.5–2.8)	3.2 (2.9–3.5)
Placement instability^d					
> 2 placement settings, <i>n</i> (%)	100,138(28.0)	54,154(44.3)	20,101(53.6)	8185(59.2)	3152(63.6)
Unadjusted OR (95% CI)	1.0 [ref]	2.0 (2.0–2.1)	3.0 (2.9–3.0)	3.7 (3.6–3.9)	4.5 (4.2–4.8)
Adjusted OR (95% CI)	1.0 [ref]	1.6 (1.6–1.6)	1.9 (1.9–2.0)	2.3 (2.2–2.4)	2.4 (2.2–2.6)
Non-permanency^e					
Non-permanency goal, <i>n</i> (%)	17, 329(5.4)	15,174(13.3)	7902(22.5)	4033(31.4)	1638(36.4)
Unadjusted OR (95% CI)	1.0 [ref]	2.7 (2.6–2.7)	5.0 (5.1–5.3)	8.1 (7.7–8.4)	10.0 (9.4–10.7)
Adjusted OR (95% CI)	1.0 [ref]	1.5 (1.4–1.5)	2.2 (2.2–2.3)	3.6 (3.5–3.7)	5.3 (5.0–5.7)

LOS = length of stay; OR = odds ratio; CI = confidence interval; ref. = reference group.

^a Missingness was 0.4% for placement instability, 5% for LOS, and 9.3% for permanency.

^b Extended length of stay in foster care defined as > 24 months versus 24 months or less. Analysis included *n* = 511,903 for unadjusted model and *n* = 436,359 for adjusted model.

^c adjusted for age, age at entry into foster care, sex, race, ethnicity, reason(s) for removal.

^d Placement instability defined as > 2 placement settings during removal versus 2 or less placements. Analysis included *n* = 536,627 for unadjusted model and *n* = 458,244 for adjusted model.

^e Non-permanency refers to a case goal plan of emancipation or long-term foster care, as opposed to permanency goals of reunification, adoption, live with relative, or guardianship. Analysis included *n* = 488,595 for unadjusted model and *n* = 419,923 for adjusted model.

the underlying racial, ethnic, and economic inequalities that may contribute to this finding.

The US DHHS, in consultation with child welfare agencies, researchers, legislators, and child advocacy organizations, identified 7 performance outcome measures for child welfare practice (Children's Bureau, 2016a). Of the 7 measures, 4 relate to placement stability, reducing LOS in foster care, and permanency. The remaining measures relate to reducing child abuse and neglect and reducing placement in group homes and institutions (Children's Bureau, 2016a). Our results show that children with increasing medical complexity are more likely to score poorly for all 7 outcomes. They are less likely to have placement stability and permanency, and more likely to have extended length of time in care, placement in a group home or institution, and have abuse or neglect as a reason for removal.

Recognizing that children with higher levels of medical complexity are at risk for poor outcomes, child health providers can contribute to interventions at the individual patient/family level and at the larger policy and health systems level. Potential strategies to enhance outcomes include: 1) Increased supports for biological parents and foster parents of children in foster care with medical complexity; 2) Enhanced communication between the various care team members—including medical team, child welfare team, school system, foster parents, biological parents (if involved); 3) Advocating the creation of databases that collect high quality data about the individual care needs and medical complexity of children in foster care to identify those at highest risk, and to track their outcomes.

4.1. Improve family supports

Some biological parents of CMC lack the resources or abilities to care for their child's medical needs and the child is placed in foster care (Seltzer et al., 2016). Some of these parents may place their child voluntarily in order to connect their child with more intensive services and supports, such as Medicaid, nursing care, specialized education services, and disability services (Hill, 2017). For CMC who are placed in specialized medical/treatment foster care placements, their foster parents receive higher reimbursement rates, specialized medical training, and specialized supports (ie. nursing, respite, and case management supports) (Seltzer et al., 2016; Williams et al., 2017). If similar supports and resources were provided to the biological family upfront, then potentially entry into foster care for this population of children might

decrease. If a child is already in care, then providing such supports to the biological parents may also make reunification more successful.

For those children who cannot remain or be reunified with their biological parents, it is important to ensure that there are appropriate placement and permanency options. There are challenges with recruiting and maintaining foster parents for CMC due to limited desire or ability to care for children with special needs (Lauver, 2008). Some CMC are placed in medical/treatment foster care homes with specialized supports, while others are placed in relative and non-relative foster care homes without such supports. Unfortunately, the AFCARS dataset does not specify whether the foster care family placement is treatment foster care. If an appropriate foster family cannot be located, then placement in a group home or institution becomes the less preferred option.

Placement instability can result if foster parents experience fatigue and burnout or are uncomfortable, unprepared, or inadequately supported in caring for the child's needs (Brown & Bednar, 2006). Foster parents of children with complex medical needs report feelings of uncertainty, frustration, and anxiety (Lauver, 2008). They report financial strain and challenges finding the time or ability to get away to manage their own self-care (Brown & Rodger, 2009). Additionally, they report that respite services and in-home nursing were crucial to maintaining their own emotional and physical health (Lauver, 2008).

When reunification is not possible, ensuring that foster parents have the necessary supports in place (i.e., home nursing, behavioral counseling, respite, transportation, care coordination, financial supports), may better position children with medical complexity to remain in home settings and achieve permanency through adoption or guardianship. For this population, it is also important to question whether long term foster care should uniformly be considered a non-permanency plan. For some medically complex children, especially those in treatment foster care settings with caregivers who are well equipped and willing to provide for the child's special needs, remaining with the same foster caregiver may be beneficial for the child. As certain financial subsidies and agency support services end when the foster parent adopts the child, foster parents may intentionally choose to remain a long term foster parent rather than lose resources.

4.2. Improve communication among care providers

While some chronic conditions are irreversible, others can be

controlled or resolved with appropriate treatment and resources, which may improve placement outcomes. Frequent and open communication among the child's care team members is essential to ensure that the child's unique care needs are being met. For each child, the composition of their care team may vary, but will likely include caregivers (i.e. foster parent(s), relatives, institution/group home staff, nurses), primary care provider, medical specialists, child welfare case workers, teachers, therapists, and biological parents (if involved). When care team members work in parallel instead of as an integrated team, efforts may be duplicated, or children may “fall through the cracks.” Consistent with AAP policy recommendations (Szilagyi et al., 2015), emphasis should be placed on care coordination and communication among providers to improve health outcomes.

Multidirectional communication is needed across systems that frequently touch the child's life (eg. health care, child welfare, school systems) in order to establish a shared set of goals to guide the child's care. Some states have embedded medical directors or nurses within their child welfare systems to facilitate such intentional collaboration between systems (Zlotnik, Wilson, Scribano, Wood, & Noonan, 2015). Working in partnership with foster parents, medical providers can assist child welfare workers by updating them about health, developmental, and behavioral care needs and recommendations to ensure that the foster parent(s)/agency is able to provide the necessary level of care. Additionally, child welfare workers have a role in keeping medical providers updated about placement changes and case goal plans that may impact how or from whom children receive their daily care. If the plan is reunification, it is important to ensure that the medical team is aware of that plan and considers the opinions and abilities of the biological parent(s) when making treatment recommendations.

Many of these children receive educational, behavioral, and developmental services (i.e. physical, occupational, speech therapies) through the school system. As such, it is important for school staff and therapists to be in regular communication with the child's other care team members to ensure that the child's individualized education plan (IEP) is appropriate and the child is receiving necessary services to achieve their highest educational and developmental potential (Hill, 2013). As children with increasing medical complexity showed higher odds of placement instability, they would also be at risk for school changes with new placements. If the new school is not updated about the child's special needs and IEP, then they may fail to provide the child with necessary supports (Geenen & Powers, 2006).

4.3. Improve data systems

Data reporting systems that collect information related to children's medical complexity and care needs could enhance the identification of children at highest risk for poor placement outcomes. However, existing foster care reporting system databases lack this level of detail. Maintaining a federally-operated data system with more specific medical complexity-related variables could support better tracking of this at-risk population on a national level instead of relying on states to independently create a data system that may be highly variable.

In 2015 the Administration for Children and Families proposed modifying the AFCARS reporting system and the final rule was published December 2016 (Government Publishing Office, 2016). This was the first modification to AFCARS since its creation in 1993 (Government Publishing Office, 2016). Several of the modifications better characterize CMC in foster care, including additional information related to children's well-being (education status; special education services; an expanded list of existing and previous physical, behavioral, and mental health conditions—expanded to 11 categories instead of 5; timeliness of health assessments), more detailed placement setting options (i.e. therapeutic foster family home, group home-family-operated, group home-staff-operated, group home-shelter care, residential treatment center, child care institution, medical or rehabilitative facility, psychiatric hospital), and further characterization of removal reasons (i.e.,

medical neglect, inadequate access to mental health or medical care services, prenatal exposure to alcohol or drugs) (Government Publishing Office, 2016).

In addition to our results supporting the proposed modifications to AFCARS, additional variables that may better define this population include ICD-10 codes, time spent on daily care needs, activities of daily living assessment, technology needs, and number of specialists caring for the child. Once systems can better identify the most severely affected children, then professionals working with children in foster care can use them to tailor interventions to the needs of these children, and to monitor their impact over time.

Prior studies have shown that there are challenges using current child welfare administrative data to secondarily evaluate disability, including 1) databases are created for child welfare administrative purposes and not research; 2) child welfare workers are not trained in disabilities or regularly identifying children with disabilities; and 3) databases do not list specific diagnoses or severity of disability (Lightfoot, 2014; Lightfoot, Hill, & LaLiberte, 2011; Shannon & Tappan, 2011). This limits the validity of disability variables available to guide policy and practice. Therefore, in addition to implementing the modifications noted above, it will be necessary to train individuals in the child welfare agency about medical complexity-related variables and ensure that they are skilled in properly coding these variables.

4.4. Strengths and limitations

A strength of the AFCARS dataset is that it includes almost all children in foster care in the US (Children's Bureau, 2014); therefore, our findings are generalizable to the US foster care system. However, several study limitations are noted related to the dataset. Child welfare agencies are organized at the state level (Children's Bureau, 2012b), creating potential for state-by-state variability in disability definitions and reporting. AFCARS is a federally mandated reporting system; data collection and entry are the responsibility of individual state agencies, which can result in variable quality and reliability. In our data sample, there was state variability in reported rates of disability, with outliers ranging from 3% (District of Columbia) to 100% (Illinois and South Carolina). Review of AFCARS data reports indicate that agencies may be underreporting or incorrectly reporting the disability data elements (Children's Bureau, 2012c). Additionally, there may be overuse of the “other” disability category if the case worker is uncertain which category to use (Children's Bureau, 2012c). Routine quality checks and AFCARS assessment reviews through the Children's Bureau may mitigate this potential limitation (Children's Bureau). These limitations further highlight the need for better data systems that accurately report health and child welfare information.

An additional limitation relates to our derived medical complexity score, which equally weights disability types, even though not all disabilities are equal in regard to the domains that define CMC—including functional limitations, healthcare utilization, and special health care needs. For example, a child with renal failure on dialysis would receive a complexity score of 1 for the “other” disability category, but may not meet criteria for the other 4 disability types. However, a child with visual impairment, ADHD, and mild intellectual disability may receive a score of 3, despite having less intense care needs than the child on dialysis. Furthermore, all children with the same disability may not have the same functional status or use of health care services. While we recognize that our scoring system is limited in this regard on the individual level, the fact that the percentage of children receiving SSI increased steadily among each increasing complexity score group suggests that the scoring system accurately captures complexity at the aggregate level.

5. Conclusion

Child health professionals, the child welfare community and the US

DHHS highly value reducing LOS in foster care and improving stability and permanency (Children's Bureau, 2016a; Szilagyi et al., 2015). Children in foster care with increasing medical complexity are at risk for undesirable placement outcomes, including extended LOS, placement instability, and being less likely to have a permanency goal. Child health providers and child welfare staff need to recognize and address the unique needs of this vulnerable population and identify strategies to improve placement outcomes.

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Conflict of interest

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