Chronic Conditions Among Children Investigated by Child Welfare: A National Sample

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KEY WORDS

child welfare investigation, chronic conditions, disparities, foster care, health status, mental health, National Survey of Child and Adolescent Well-Being, NSCAW

ABBREVIATIONS

CHC—chronic health conditions
NSCAW—National Survey of Child and Adolescent Well-Being
PSU—primary sampling unit
QuICCC-R—Questionnaire for Identifying Children With Chronic Conditions–Revised

Dr Stein conceptualized and designed the study and drafted the initial manuscript and its subsequent revisions; Dr Hurlburt participated in the design of the study and critically reviewed several drafts of the manuscript; Dr Heneghan participated in the conceptualization and design of the study and critically reviewed several drafts of the manuscript; Ms Zhang conducted the initial analyses, and reviewed and helped revised the manuscript; Ms Rolls-Reutz participated in the design of the study and critically reviewed the manuscript; Dr Silver performed part of the data analysis and critically reviewed the manuscript; Ms Fisher participated in the design of the study and critically reviewed the manuscript; Dr Landsverk obtained the data set, supervised the project, and critically reviewed the manuscript; and Dr Horwitz participated in the conceptualization and design of the study and critically reviewed several drafts of the manuscript. All authors approved the final manuscript as submitted.

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WHAT'S KNOWN ON THIS SUBJECT: Most studies focus on health of foster children or local samples of young children. One previous study examined a national cohort longitudinally but did not address the full age group or range of conditions at the time of initial investigation.

WHAT THIS STUDY ADDS: Using 2 approaches to assess children (aged 0–17.5 years) who have chronic health conditions, we found that regardless of placement, investigated children had much higher rates of these conditions than the general population at the time of initial assessment.

abstract

OBJECTIVE: To assess the presence of chronic health conditions (CHCs) among a nationally representative sample of children investigated by child welfare agencies.

METHODS: The study included 5872 children, aged 0 to 17.5 years, whose families were investigated for maltreatment between February 2008 and April 2009. Using data from the second National Survey of Child and Adolescent Well-Being, we examined the proportion of children who had CHC. We developed 2 categorical and 2 noncategorical measures of CHC from the available data and analyzed them by using bivariate and multivariable analyses.

RESULTS: Depending on the measure used, 30.6% to 49.0% of all children investigated were reported by their caregivers to have a CHC. Furthermore, the children identified by using diverse methods were not entirely overlapping. In the multivariable analyses, children with poorer health were more likely to be male, older, and receiving special educational services but not more likely to be in out-of-home placements.

CONCLUSIONS: The finding that a much higher proportion of these children have CHC than in the general population underscores the substantial health problems of children investigated by child welfare agencies and the need to monitor their health carefully, regardless of their placement postinvestigation. *Pediatrics* 2013;131:455–462

The complex physical and mental health care needs of children entering the foster care system have been realized for several decades. It is well documented that these children have considerable unmet health care needs both because of chronic health conditions (CHC) and challenging family environments.[1–4] Some studies show that children with higher rates of CHC and special health care needs are more likely to be placed out-of-home than those who are healthier.[5–8] However, many reports are limited by use of local samples, clinical reports, or weak and inconsistent measures of CHC. Some assess only the large number of younger children who come to the attention of child welfare agencies, rather than consider the full age span, and most focus on children placed outside their families, despite the fact that >80% of children investigated for possible maltreatment remain in their own homes.[9] Thus, the selectivity of previous samples and methods of ascertaining the presence of CHC may influence findings regarding their prevalence.

Only 1 report of children investigated by child welfare agencies examined health status in a nationally representative sample of children irrespective of placement. Ringeisen et al[7] used National Survey of Child and Adolescent Well-Being I (NSCAW I) data to report on children <15 years old who had contact with child welfare services beginning in 1999. They reported baseline rates of CHC of 14.9% according to a list of 22 health problems defined as those that "last a long time or come back again and again" and of developmental needs of 19.2%, for a total of 35.1% of the population. At the end of 3 years, using a long list of conditions available in the data set, children who were adopted and those in foster care had higher odds of having special health care needs and developmental needs than those remaining with their families. Overall, 50.3% of children had such issues at some time over the 3-year period of the study.

There has been debate about how to measure the presence of CHC. There are proponents of both diagnostic and noncategorical (or generic) approaches.[10–13] Detection through the use of diagnostic approaches tends to vary with the content and length of the list of diagnostic categories and with the respondents' understanding of the umbrella term used, as well as of what is meant when the respondent is asked about "other similar conditions." Although many researchers have used diagnostic lists, the noncategorical or generic approach, originally espoused by Pless and Pinkerton,[14] has been widely endorsed because it is less dependent on specific knowledge of medical diagnoses.[15–17] This approach is based on the consequences that conditions have on the lives of people and has been operationalized by using a family of measures.[18–21] It is also worth noting that most current noncategorical methods do not distinguish between physical and mental health issues or developmental or cognitive disabilities as causes of CHC but are inherently designed to identify any ongoing condition affecting an individual. Diagnostic lists sometimes do and sometimes do not include these types of conditions, depending on the specific conditions included on the list.

In an effort to understand the nature of CHC of the children and youth investigated by child welfare organizations, the Administration for Children and Families augmented the health data they collected in NSCAW I by adding both diagnostic categories and noncategorical items to NSCAW II, a replication survey conducted a decade after NSCAW I.[22] Thus, a recently released data set provides a unique opportunity to examine the health of a nationally representative sample of children and youth investigated by child welfare agencies by using multiple measures of CHC. Moreover, it allows examination of CHC across the entire age continuum from 0 to 17.5 years and regardless of placement decision at the time of investigation. The purpose of the current report is to describe the characteristics of the investigated population in terms of the proportion with CHC, by using multiple measures, and to assess the degree of overlap between the methods. It is our expectation that the combination of methods will provide a more robust assessment of overall health of children than any 1 measure alone and that this data set will allow us to see how health status differs across placement settings.

METHODS

Design and Analytic Sample

We used data from NSCAW II, a study of 5872 youth ages 0 to 17.5 years referred to US child welfare agencies for whom an investigation of potential maltreatment was completed between February 2008 and April 2009.[22] Initial interviews were conducted within ~4 months of completed child welfare investigations. NSCAW II, like its predecessor NSCAW I, used a national probability sampling strategy to select primary sampling units (PSUs), typically counties, from which a sample of children was drawn. The same PSUs were included whenever possible. Only 71 of the 92 original PSUs in NSCAW I were eligible and agreed to participate in NSCAW II; 10 additional PSUs were added to replace the PSUs that declined to participate. This sample was constructed to be representative of all US children who were subjects of agency investigations for alleged maltreatment during the sampling period, and it is to this population that the results are generalizable.

Survey Design and Assessment Procedures

Data come from the baseline interviews with caregivers and children (≥11 years) completed between March 2008 and September 2009. All procedures for NSCAW II were approved by the Research Triangle Institute's institutional review board and all analytic work on the NSCAW II de-identified data were approved by the Rady Children's Hospital institutional review board.

Measures

Sociodemographic variables included child's age, gender, race, and placement-related variables, including placement at the time of the baseline interview. The age, marital status, education, and health status of current caregivers were available. Age of caregivers was grouped as follows: ≤24, 25 to 34, 35 to 44, 45 to 54, and ≥55 years. Education was categorized as less than high school graduate, high school graduate, or more than high school education. The health status of the current caregiver was self-rated and dichotomized as excellent or very good versus good, fair, or poor. Insurance status was classified hierarchically as any federal insurance, state insurance, private or other, or no insurance. Children's current placement was dichotomized into in-home and out-of-home placements. Experience of a previous out-of-home placement was categorized as a yes/no variable.

Overall Assessment of Health

Caregivers were asked to rate the child's overall health by using the standard question "How would you rate ______'s overall health: excellent, very good, good, fair, poor?" Answers were dichotomized to excellent, very good versus good, fair, or poor. This categorization has been widely used because most parents categorize children's health as excellent or very good and because of information about how social desirability affects the way people answer such questions.[23,24]

Presence of CHC

Two different approaches were used to measure CHC. The first was based on a noncategorical or generic measure of CHC that is not dependent on diagnosis but is based on consequences of conditions in the lives of children. Parts of the 16-item Questionnaire for Identifying Children With Chronic Conditions–Revised (QuICCC-R)[18] were included in the caregiver's interview and served as the noncategorical measure. The second approach was based on diagnostic information in the interviews.

Noncategorical Measure

As mentioned earlier, the QuICCC-R is constructed by using statements about condition consequences plus probes for most items on the cause and duration of the consequences. The probes are necessary to ensure that the condition is chronic. Unfortunately, QuICCC-R questions about some of the most frequently observed consequences for children (eg, medication use, hospitalization) were omitted from the NSCAW II survey. Moreover, the probes that are part of most questions in the instrument were included inconsistently. Because we could not ascertain chronicity of those consequences, we coded the NSCAW II data in 2 ways: first, conservatively or restrictively to include only consequences that we knew were chronic; and second, liberally or more inclusively to include conditions for which the duration was unknown. The conservative interpretation used only the 8 items that were given in their original format (life-threatening allergies; serious delay in physical growth and development; serious delay in emotional growth and development with appropriate probes for chronicity where indicated; whether the child had to reduce the amount of time or effort he or she could exert in an activity [compared with age-mates]; being blind or nearly blind with glasses; being deaf; difficulty understanding simple instructions [for those aged ≥3 years]; and difficulty being understood by others [for those aged ≥4 years]). A separate analysis using the validation sample for the QuICCC-R[19] showed that this list of included items identified 29% of children identified by the full measure. The liberal interpretation included positive responses to the stem questions (the consequences) for all the aforementioned items (without the usual probes for cause and duration) along with items assessing receipt of physical, occupational, speech and language, or mobility therapy; need for special arrangements or equipment; and unmet need for special services. A separate analysis indicated that this list of items identified 42.5% of the subjects identified by using the full QuICCC-R but that 6.5% of the screened children would ordinarily have been excluded by the use of the correct probes. Thus, the true percentage of the sample accurately identified by this set of items was 36% of the validation sample.[18] Using these 2 sets of items, any child with ≥1 positive response to the included QUICCC-R questions was considered to have a CHC according to the liberal definition.

Diagnostic List of Medical Conditions

The data set included a list of diagnostic categories, but some covered broad diagnostic groupings that may or may not be chronic or were subject to interpretation by the respondent; we therefore could not determine whether an identified child actually had a CHC. Therefore, we used clinical and epidemiologic criteria to construct 2 variables: 1 conservative or restrictive and 1 liberal or inclusive. The conservative list of diagnoses included conditions that are usually considered chronic: asthma, attention-deficit/hyperactivity disorder, AIDS, autism, Down syndrome, diabetes, cystic fibrosis, mental retardation/developmental disabilities, cerebral palsy, and muscular dystrophy. The liberal list added other conditions for which chronicity is possible but uncertain: heart problems, hypertension, blood problems, migraines/frequent headaches, arthritis/joint problems, dental problems, repeated ear infections, and back/neck problems; currently having depression, anxiety, or an eating disorder; and "other health problems." Neither list was weighted for severity because there was no way to assess this factor given the available data.

Analyses

Analyses used descriptive statistics to summarize key variables of interest for the overall sample and for the children identified as having CHCs according to each of the 4 methods. Significance of bivariate associations was assessed first by using χ^2 tests for categorical variables and subsequently with multivariable logistic regression analyses. All analyses presented here, unless otherwise noted, were conducted by using weighted data. Analysis weights were constructed corresponding to the stages of the sample design, accounting for the probability of county selection and the probability of each child's selection within a county (given the youth's county of residence). Nonweighted cell sizes are presented for some analyses to provide details about the amount of data on which analyses are based. All estimates (ie, means, percentages) were generated by using the weights supplied by NSCAW and therefore can be inferred to the population of US children who were the subject of child welfare investigations. All analyses were conducted by using SAS-Callable SUDAAN version 10.0.1 (Research Triangle Institute, Research Triangle Park, NC).[15,25,26]

RESULTS

Baseline characteristics for children and their families are shown in Table 1. More than 40% of the children were <6 years old and white. Twenty-eight percent had previous child welfare reports and ~13% were in out-of-home placements. Most lived with caregivers whose own health was compromised. Almost one-quarter of children were receiving special services at school, and ~10% had no insurance. Using the noncategorical measures, the conservative and liberal definitions identified 30.6% and 41.1%, respectively, as having CHC. The diagnostic list methods generated estimates of 31.6% and 49.0%.

Table 2 displays the proportion of children with each characteristic who had CHC according to each of the 4 measures. On all measures, children who were ≥6 years of age and male were more likely to have CHC. Those with a history of child welfare agency contact, out-of-home placements, and living with older caregivers and caregivers in poorer health also had higher rates of CHC.

Table 3 displays the results of the 4 separate multivariable analyses and the odds ratios for the statistically significant variables related to each of the 4 CHC outcome measures. The multivariable logistic regressions generally confirm the results of the bivariate analyses except for caregiver age, for which the association

TABLE 1 Sample Characteristics (*N* = 5872)

Characteristic	% (SE)
Demographic information	
Child age's, y	
0–5	43.2 (1.2)
6–10	27.6 (0.9)
≥11	29.2 (1.2)
Child's gender	
Male	50.9 (1.2)
Female	49.1 (1.2)
Child's race	
Black	22.8 (2.7)
White	41.9 (3.9)
Hispanic	27.8 (3.5)
Other	7.6 (1.0)
Child's welfare history	
Yes	28.0 (1.6)
No	72.0 (1.6)
Placement	
In home	87.1 (1.1)
Out-of-home	12.9 (1.1)
Current caregiver's age, y	
≤24	16.5 (1.2)
25–34	40.6 (1.4)
35–44	27.1 (1.4)
45–54	11.2 (0.9)
≥55	4.6 (0.5)
Caregiver's overall health: good/fair/poor	55.6 (1.2)
Special education/currently have IFSP/IEP	23.7 (1.4)
Insurance type	
Any federal	73.2 (1.7)
State with or without other	4.0 (0.8)
Private/other	13.1 (1.2)
No insurance	9.7 (0.9)
Child's overall health: good/fair/poor	23.0 (1.3)
Presence of noncategorical chronic condition (conservative)	30.6 (1.6)
Presence of noncategorical chronic condition (liberal)	41.1 (1.6)
Diagnostic chronic condition (conservative)	31.6 (1.1)
Diagnostic chronic condition (liberal)	49.0 (1.3)

IFSP/IEP, Individual Family Service Plan/Individualized Education Program.

TABLE 2 Bivariate Analysis of Proportion of Children With Chronic Conditions Assessed by Using 4 Different Measures

Characteristic	Noncategorical: Partial QuICCC-R		Diagnostic List	
	Conservative (30.6%)	Liberal (41.1%)	Conservative (31.6%)	Liberal (49.0%)
Demographic information				
Child's age, y	***	***	***	***
0–5	19.9 (1.7)	24.5 (2.1)	19.1 (1.8)	34.8 (2.0)
6–10	41.4 (2.3)	55.4 (2.5)	40.8 (2.4)	55.5 (2.3)
≥11	36.5 (2.9)	52.7 (3.0)	41.6 (2.9)	64.2 (2.8)
Child's gender	***	***	***	**
Male	35.0 (2.2)	45.8 (2.2)	38.4 (1.4)	53.1 (1.7)
Female	26.1 (1.5)	36.4 (1.8)	24.6 (1.7)	44.7 (2.1)
Child's race				*
Black	31.7 (2.0)	40.4 (2.3)	31.6 (2.2)	46.5 (2.6)
White	30.6 (2.4)	41.9 (2.5)	35.2 (1.9)	53.3 (1.8)
Hispanic	31.4 (2.6)	41.9 (2.4)	26.5 (2.2)	43.4 (2.8)
Other	25.0 (3.6)	37.5 (5.1)	31.2 (4.5)	55.1 (5.3)
Child's welfare history	***	***		**
Yes	38.5 (2.6)	49.7 (2.8)	37.3 (2.8)	58.1 (2.5)
No	27.7 (1.7)	38.2 (1.8)	30.9 (1.3)	48.3 (1.5)
Placement	*	*		**
In home	29.4 (1.7)	40.0 (1.7)	31.0 (1.2)	47.9 (1.3)
Out-of-home	39.0 (3.2)	48.7 (2.9)	35.5 (2.4)	56.0 (2.5)
Current caregiver's age, y	**	***	***	***
≤24	16.2 (2.5)	20.1 (2.2)	18.7 (2.8)	34.0 (2.8)
25–34	32.7 (2.3)	43.2 (2.2)	30.8 (1.8)	46.1 (2.1)
35–44	33.0 (3.0)	46.0 (2.7)	35.8 (2.2)	56.4 (2.6)
45–54	33.9 (4.4)	46.9 (4.7)	35.8 (3.8)	54.9 (4.1)
≥55	39.9 (4.5)	53.6 (4.4)	50.6 (4.2)	68.0 (4.3)
Caregiver's overall health	**	***	**	***
Good/fair/poor	34.4 (2.1)	47.1 (2.2)	36.0 (1.9)	54.3 (2.0)
Excellent/very good	25.5 (1.7)	33.5 (1.9)	26.0 (1.6)	42.3 (2.0)
Special school services	***	***	***	***
Yes	59.7 (2.6)	78.7 (2.1)	64.0 (2.1)	81.3 (2.0)
No	21.5 (1.3)	29.4 (1.4)	21.4 (1.1)	38.9 (1.4)
Insurance type		*		
Any federal	31.4 (2.0)	42.2 (2.0)	32.9 (1.3)	49.7 (1.5)
State with or without other	38.1 (7.4)	54.1 (6.2)	35.5 (6.1)	51.2 (6.0)
Private/other	24.3 (2.6)	34.4 (3.0)	31.5 (3.8)	52.1 (4.6)
No insurance	30.4 (5.0)	37.0 (4.8)	20.2 (4.3)	38.3 (4.8)

Overall percentages are given in parentheses for each column. Data are presented as % (SE).

* $P < .05$,

** $P < .01$,

*** $P < .001$ for comparisons of children by each characteristic within the identification category.

disappears, and out-of-home placements, which holds only for the noncategorical measure.

Finally, we examined the degree to which these methods identified the same versus different children. The level of agreement between each pair of the 4 methods of identification varied from 45% to 70%. In total, 61.5% of children were positive for CHC by 1 or more methods of identification; 15% of children met criteria for 1 method, 19.7% for 2 methods, 9.4% for 3 methods, and 17.4% for all 4 methods of identification.

DISCUSSION

This study is the first to examine the rates of CHC in a national sample of children from birth through adolescence who were investigated by child welfare agencies. As noted earlier, most of these children remain in their homes. Our findings are dramatic in showing that when compared with the health of the nation's children as a whole, the proportions of investigated children affected by health challenges are far higher by every method used than are the usual national population-based rates of CHC of 12.8% to 19.3% in the literature.[27] The most recent estimates use a short noncategorical screener on population-based samples[20] and include high-frequency items such as taking medicines prescribed by a physician for a condition that has lasted or is expected to last for >1 year, which were omitted in the NSCAW II noncategorical measures. Despite the possibility that some children investigated by the welfare system were misclassified for this reason, our findings suggested a prevalence of CHC that was >1.5 times that of the general US population. Although there is some

TABLE 3 Summary of Significant Predictors in Logistic Regressions Predicting Presence of Health Problems

Sample Characteristics	Noncategorical: Partial QuICCC-R		Diagnostic List	
	Conservative (*n* = 5739)	Liberal (*n* = 5739)	Conservative (*n* = 5739)	Liberal (*n* = 5722)
Child's age, y				
0–5	Ref	Ref	Ref	Ref
6–10	1.71 (1.19–2.45)**	2.35 (1.67–3.31)***	1.80 (1.25–2.60)**	1.47 (1.08–2.00)*
≥11	1.26 (0.89–1.78)	1.84 (1.27–2.67)**	1.70 (1.20–2.41)**	1.95 (1.41–2.70)***
Child's gender				
Female	Ref	Ref	Ref	Ref
Male	1.42 (1.13–1.79)**	1.44 (1.13–1.84)**	1.92 (1.49–2.46)***	1.39 (1.07–1.79)*
Child's race				
White				Ref
Black				0.86 (0.64–1.15)
Hispanic				0.70 (0.53–0.94)*
Other				1.14 (0.73–1.78)
Placement				
In home	Ref	Ref		Ref
Out-of-home	1.78 (1.22– 2.62)**	1.39 (1.00–1.94); *P* = .0503		1.18 (0.91–1.53)
Current caregiver's age, y				
≤24	0.80 (0.38–1.68)	0.59 (0.30–0.15)	0.40 (0.22–0.74)**	0.50 (0.28–0.89)*
25–34	1.25 (0.76–2.04)	1.01(0.69–1.46)	0.44 (0.30– 0.66)***	0.50 (0.30– 0.84)*
35–44	1.10 (0.61–1.99)	0.98 (0.59–1.62)	0.49 (0.31– 0.77)**	0.63 (0.37– 1.08)
45–54	0.89 (0.48–1.64)	0.81 (0.43–1.50)	0.45 (0.26– 0.77)**	0.55 (0.30–0.99)*
≥55	Ref	Ref	Ref	Ref
Caregiver's overall health				
Excellent/very good	Ref	Ref	Ref	Ref
Good/fair/poor	1.48 (1.15–1.91)**	1.78 (1.34– 2.35)***	1.55 (1.17–2.04)**	1.61 (1.26–2.07)***
Special school services	4.52 (3.43–5.97)***	6.51 (4.80–8.83)***	4.91 (3.78– 6.37)***	5.08 (3.67–7.03)***
Insurance type				
Any federal		Ref		
State with or without other		1.26 (0.76–2.10)		
Private/other		0.56 (0.39–0.81)*		
No insurance		0.75 (0.47–1.19)		

Data are presented as odds ratio (95% confidence interval).
* $P < .05$,
** $P < .01$,
*** $P < .001$.

evidence in national samples that poorer children, who are overrepresented in this sample, have higher rates of CHC, it is also true that prevalence increases greatly with age. More than 50% of the children in this sample are young, which also suggests that the percentage with CHC should be lower than the national rates. Furthermore, there is overrepresentation of minority children in the sample, and minority children are also less likely to be identified by using noncategorical measures.[28] Moreover, the noncategorical measures that identified 30.6% to 41.1% of the sample are likely gross underestimates of the prevalence of CHC because neither identifies >36% of the children who were identified by using the full set of questions in the QuICCC-R. This result suggests that the true prevalence of CHC among children investigated by child welfare agencies is at least double what is identified according to the existing subset of questions. The diagnostic measures, which only partially overlap in the children they identify, identified 31.6% and 49.0%, compared with the rate of 35.1% at intake identified by Ringeisen et al.[7]

A major strength of the current study is that it provides a unique window on the health of these vulnerable children more generally than previous reports that focused only on the health of children who were removed from their homes. Furthermore, the use of multiple measures of health status, including both conservative and liberal estimates of the rates of CHC by using 2 different methods of ascertainment, enables us to assess the robustness of the pattern, rather than relying on 1 subjective estimate of overall health status. This is extremely important because of the degree to which the number identified is method dependent.[29] It is also interesting to see that the patterns are relatively stable despite use of both a noncategorical questionnaire and diagnostic lists.

As with all reports based on secondary analyses, there are limitations to this study. As noted, the entire set of QuICCC-R questions[19] was not included in the NSCAW II interviews. Omission of the most frequently positive QuICCC-R questions (eg, use of prescription medications or being hospitalized for a condition of 12-month duration that the child still has) clearly lowers the estimate of the number of children affected by CHC. In other areas, there were data collected that we could not use. For example, we opted to exclude some questions on past health care use that might have enriched these analyses because of variations in the recall periods on which caregivers reported (eg, 1 year if they were in their own homes and the length of time the child has been placed if not). We also acknowledge that the conditions of the out-of-home children may have been underreported in some cases because of the shorter duration of their time with caregivers. However, we do not believe that this significantly altered the patterns reported because in the case of serious ongoing health conditions, our experience is that they are more likely to be recognized in the foster system than in their original homes.

We believe this report provides an important window on the health of children in the United States who are investigated by the child welfare system. These findings can be generalized to a large population of children at high risk: namely, the 5.9 million children identified in 3.3 million child welfare reports, of whom >60% are investigated for potential abuse and neglect.

Based on NSCAW I data, Ringeisen et al[7] suggested that the cumulative burden of CHC and special needs among children in the child welfare system is substantial. Our analyses extend that finding by showing that even at the time of their initial assessments, more children have health problems than previously recognized. These results emphasize the importance of making sure these extensive health care needs are being addressed by the child welfare system and of developing robust ways to track how these patterns change over time.

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