

What Factors Are Associated With State Performance on Provision of Transition Services to CSHCN?

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KEY WORDS

children with special health care needs, CSHCN, Maternal and Health Child Bureau, MCHB, 2005–2006 National Survey of Children With Special Health Care Needs, NS-CSHCN, transition to adulthood, Title V, Healthy People 2010, HP2010

ABBREVIATIONS

CSHCN—children with special health care needs
MCHB—Maternal and Child Health Bureau
NS-CSHCN—2005–2006 National Survey of Children With Special Health Care Needs
FPL—federal poverty level
MSA—metropolitan statistical area
OR—odds ratio
CI—confidence interval
aOR—adjusted odds ratio

www.pediatrics.org/cgi/doi/10.1542/peds.2009-1255H

doi:10.1542/peds.2009-1255H

Accepted for publication Aug 3, 2009

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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

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FINANCIAL DISCLOSURE: The authors have indicated they have no financial relationships relevant to this article to disclose.

abstract

OBJECTIVE: To examine whether individual, condition-related, and system-related characteristics are associated with state performance (high, medium, low) on the provision of transition services to children with special health care needs (CSHCN).

METHODS: We conducted descriptive, bivariate, and multivariable analyses of 16 876 children aged 12 to 17 years by using data from the 2005–2006 National Survey of Children With Special Health Care Needs. Polytomous logistic regression was used to compare the characteristics of CSHCN residing within high-, medium-, and low-performance states, with low-performance states serving as the reference group.

RESULTS: Compared with non-Hispanic white CSHCN, Hispanic (adjusted odds ratio [aOR]: 0.25 [95% confidence interval (CI): 0.17–0.37]) and non-Hispanic black (aOR: 0.44 [95% CI: 0.30–0.62]) CSHCN were less likely to reside in a high-performance than in a low-performance state. Compared with CSHCN who had a medical home or adequate insurance coverage, CSHCN who did not have a medical home or adequate insurance coverage were less likely to reside in a high-performance than in a low-performance state (aOR: 0.73 [95% CI: 0.57–0.95]; aOR: 0.73 [95% CI: 0.58–0.93], respectively).

CONCLUSIONS: Key factors found to be important in a state's performance on provision of transition services to CSHCN were race/ethnicity and having a medical home and adequate insurance coverage. Efforts to support the Maternal and Child Health Bureau's integration of system-level factors in quality-improvement activities, particularly establishing a medical home and attaining and maintaining adequate insurance, are likely to help states improve their performance on provision of transition services. *Pediatrics* 2009;124:S375–S383

Transition services are defined as the “purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems.”¹ Nearly 90% of children with special health care needs (CSHCN) now survive to adulthood.^{1–4} Although many CSHCN make a smooth transition from pediatric to adult health care,⁵ most CSHCN have ongoing health needs and higher lifetime medical expenditures compared with other children, which makes transition services critical for ensuring the continued receipt of medically and developmentally appropriate health care.^{6–12} In addition, CSHCN with more severe medical conditions or who require more intensive services often face different challenges in their transition to adult health care, partly because of the nature of and costs associated with the services required.^{13–16}

In recognition of the importance of transition services, the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration added “receipt of the services necessary to make transitions to all aspects of adult life” as 1 of 6 system indicators to measure state and national progress toward implementing community-based systems of services for CSHCN.¹⁷ The 2005–2006 National Survey of Children With Special Health Care Needs (NS-CSHCN) was developed to provide state and national prevalence estimates for assessing progress toward federal and state objectives and to inform state Title V needs assessments.¹⁸ Given the priority placed on transition services, providers and policy makers need current information to better understand the factors associated with the receipt of transition services and progress made toward achieving system indicators and

Healthy People 2010 goals to improve service systems for CSHCN.¹⁸

Numerous researchers have reported that individual, condition-related, and system-related factors influence access to health care and transition services for CSHCN.^{7,19–32} Lotstein et al¹⁹ reported that failure to obtain transition services may lead to gaps in insurance coverage and delayed care for low-income youth who have aged out of Title V CSHCN services. In this article, we examine whether and to what extent individual, condition-related, and system-related characteristics are associated with state performance in the provision of transition services to CSHCN.

METHODS

We conducted an analysis of cross-sectional data from the NS-CSHCN by using a subpopulation of children aged 12 to 17 years ($N = 16\,876$). We explored whether state performance on the provision of transition services (high, medium, low) was associated with individual demographic and family characteristics (ie, child’s age, race/ethnicity, family structure, household education level, family income), condition-related factors, and the 5 MCHB-defined system indicators described below.

Outcome Variable

The state performance outcome variable was developed in a multistep process.³³ First, 5 questions from the household interview were used to determine if a child had received transition services: he or she must have indicated that his or her doctors have either discussed transitioning to doctors who treat adults, changing health needs as a youth becomes an adult, and/or how to maintain health insurance coverage on reaching adulthood or that such discussions were not needed; and indicated that his or her

doctors usually or always encourage him or her to take age-appropriate responsibility for managing his or her own health care needs.³⁴ Next, the percentage of CSHCN in each state who received transition services was tabulated, and each state was compared with the national average of 41.2% for provision of transition services. High-performance states (Missouri, Nebraska, Minnesota, Vermont, New Hampshire, North Dakota, South Dakota, Kansas, Maine, Ohio, Iowa, and Washington) were those in which the proportion of CSHCN who received transition services was significantly higher (range: 47.3%–54.4%) than the national average. Medium-performance states (Colorado, Wyoming, Massachusetts, Montana, Pennsylvania, Idaho, Wisconsin, Illinois, Oklahoma, Oregon, Connecticut, Kentucky, Utah, Delaware, Alaska, Nevada, West Virginia, Indiana, Louisiana, Michigan, North Carolina, Tennessee, Arizona, Hawaii, New York, Alabama, New Jersey, Virginia, Rhode Island, Maryland, South Carolina, California, Texas, and Georgia) were those in which the percentage was not significantly different (range: 37.5%–47.0%) from the national average. Low-performance states (Florida, New Mexico, Arkansas, Mississippi, and District of Columbia) were those in which the percentage was significantly lower (range: 24.0%–33.8%) than the national average.^{17,33}

Explanatory Variables

With the exception of age, which was maintained as a continuous variable, the categorical explanatory variables were classified or reclassified as follows. Race and ethnicity were reclassified into a single variable: Hispanic; non-Hispanic black; and non-Hispanic white. CSHCN of other racial/ethnic origins were excluded from this analysis because of the small sample size. Household education (highest level of education received by a parent) was

classified into 3 levels: less than high school; high school; and more than high school. Family household structure was classified into 2-parent households with 2 biological or adoptive parents; 2-parent households with 1 step-parent; 1-parent households (mother only, no father figure); and all other family household compositions.³⁵ Family poverty level was based on the imputed variable for family incomes: 0% to 99% of the federal poverty level (FPL); 100% to 199% of the FPL; 200% to 399% of the FPL; and $\geq 400\%$ of the FPL.³⁶ Residence was classified as specified in the NS-CSHCN: metropolitan statistical areas (MSAs); non-MSAs; and areas in which the population was $< 500\,000$.³⁵

CSHCN screener questions were used to characterize both type and intensity of need (prescription medications only, services only, prescription medications and services, and functional limitations) among the children.³⁷ To assess the frequency with which “medical, behavioral, or other health conditions/emotional, developmental, or behavioral problems” affected children, we evaluated number of days missed from school, impact of conditions/problems on a child’s ability to do things (a great deal, some, or very little), and impact of conditions/problems on a child’s ability to do things that other children of the same age do (usually/always versus sometimes/never).³⁵

The system-related variables that reflect the performance of state health systems on MCHB-defined system indicators and/or selected subcomponents thereof included (1) families of CSHCN are decision-making partners in all levels of care and are satisfied with their care, (2) CSHCN receive coordinated care in a medical home, (3) families of CSHCN have adequate insurance coverage, (4) children are screened early and continuously for special health needs; and (5) community-based services are orga-

nized so that families can use them easily. These system-related variables are based on parental responses to 1 or more NS-CSHCN questions and were classified as dichotomous variables.³⁵

Statistical Analyses

We estimated the prevalence and 95% confidence intervals (CIs) of CSHCN reported to have received transition services (ie, the child received 4 types of anticipatory guidance and was usually or always encouraged to take responsibility for his or her own health care) according to each of the explanatory variables.

In bivariate analyses, crude odds ratios (ORs) and 95% CIs were estimated to examine associations between the explanatory variables and state performance on transition services. Confounding was assessed by comparing crude ORs to adjusted odds ratios (aORs). Variables that exhibited a difference of 10% or more between crude ORs and aORs were deemed as potential confounders and retained in modeling.

We used a multilevel modeling model framework³⁸ to account for the clustered sampling design (ie, children sampled within states), obtain correct estimated SEs for clustered data, and investigate whether ORs for state performance and the explanatory variables varied across clusters (ie, states). In the first analytic step, we used MLwiN³⁹ and methods by Korn⁴⁰ and Carle⁴¹ to subset the data and scale the weights, respectively. No variance across clusters was observed; therefore, polytomous logistic regression models⁴² were constructed to examine associations between high, medium, and low state performance on the receipt of transition services and individual, condition-related, and system-related characteristics. Low-performance states served as the referent group. We created and recoded variables by using SAS 9.1.3 (SAS Insti-

tute, Inc, Cary, NC). Analyses were conducted by using SAS-callable SUDAAN 9 (Research Triangle Institute, Research Triangle Park, NC) to appropriately weight estimates and adjust for the complex sampling design.⁴³ We followed a stepwise backward elimination strategy to eliminate variables from starting models containing all main effects and 2-way interaction terms. We used P values of $> .1$ as the elimination criterion and P values of $\leq .05$ as the threshold for statistical significance. Potential confounders (race/ethnicity, household education level, family household structure, and family poverty level) were retained in final adjusted models. We did not adjust for multiple comparisons.

RESULTS

The proportion of CSHCN encouraged to take responsibility for their health care needs (73.3%) was approximately double that of those who received anticipatory guidance (38%) or who received the services necessary to make transitions to all aspects of adult life (transition services) (41%) (see Table 1). Having a medical home and feeling satisfied with the care received were more frequently reported health system characteristics among those who reported receiving transition services and its subcomponents. Demographic and other characteristics associated with receipt of transition services and its subcomponents included CSHCN who were non-Hispanic white; household education levels greater than high school; household structures with 2 parents; and household incomes of $> 400\%$ FPL (all statistically significant at $P \leq .05$). The proportion of CSHCN who needed only prescription medications or who had conditions with low impact on their abilities was greater than other condition-related characteristics in relation to receipt of transition services and its subcomponents.

TABLE 1 Individual, Condition-Related, and System-Related Characteristics of CSHCN Aged 12 to 17 Years (*N* = 16 876)^a Who Received Only Anticipatory Guidance, Were Only Encouraged to Take Responsibility for Health Care Needs, or Received All of the Services Necessary to Make Transitions to All Aspects of Adult Life: 2005–2006 National Survey of CSHCN

	Child Received Anticipatory Guidance (<i>N</i> = 5519 [38.1%]) ^b			Child Usually or Always Encouraged to Take Responsibility for Own Health Care Needs (<i>N</i> = 13 486 [78.3%]) ^c			Child Received Transition Services (<i>N</i> = 6992 [41.4%]) ^d		
	<i>n</i>	Weighted %	95% CI	<i>n</i>	Weighted %	95% CI	<i>n</i>	Weighted %	95% CI
Individual characteristics									
Race/ethnicity									
Hispanic	380	25.8	21.4–30.8	1123	70.4	66.3–74.2	430	26.3	22.2–30.9
Non-Hispanic black	413	27.2	23.9–30.8	1288	73.2	69.8–76.4	455	28.7	25.4–32.1
Non-Hispanic white	4726	42.8	41.3–44.4	11 075	80.6	79.4–81.8	6107	46.5	45.0–48.0
Household education level									
Less than high school	163	23.7	19.1–28.9	504	65.7	60.0–71.0	162	21.6	17.4–26.6
High school	720	31.3	28.4–34.3	2015	74.8	72.3–77.2	833	31.7	29.0–34.6
More than high school	4631	42.1	40.5–43.7	10 949	80.7	79.4–81.9	5990	46.5	45.0–48.0
Family household structure									
2-parent household (2 biological/adoptive parents)	3077	44.1	42.0–46.1	7156	81.9	80.4–83.3	4117	48.7	46.8–50.6
2-parent household (2-parent step-families)	750	38.8	35.1–42.6	1786	77.9	74.2–81.2	889	40.6	36.9–44.4
1-parent household (mother only)	1198	31.1	28.7–33.6	3330	74.5	72.3–76.7	1409	32.8	30.5–35.2
Other family household structures	311	36.2	30.6–42.3	723	72.8	67.6–77.5	369	38.1	32.7–43.8
Family poverty level, % FPL									
0–99	504	25.1	22.2–28.3	1599	69.4	66.2–72.4	535	24.3	21.5–27.3
100–199	912	31.9	28.8–35.1	2552	75.1	72.4–77.7	1093	34.1	31.0–37.2
200–399	1937	40.8	38.3–43.3	4582	79.7	77.8–81.5	2444	43.6	41.3–45.9
≥400	2166	48.4	45.9–51.0	4753	84.2	82.3–85.9	2920	53.7	51.4–56.0
Residence									
MSA	2846	37.1	35.4–38.9	7262	77.9	76.4–79.2	3698	40.8	39.2–42.5
Non-MSA	863	40.6	37.6–43.7	2054	79.7	77.3–81.9	1034	42.4	39.5–45.3
<500 000 in nonmetropolitan areas ^e	782	39.2	36.0–42.5	1923	78.3	75.6–80.8	1006	42.7	39.7–45.8
<500 000 in metropolitan areas ^f	408	46.2	42.4–50.1	887	81.7	78.8–84.2	490	47.4	43.9–51.0
<500 000 in nonmetropolitan and metropolitan areas ^g	620	47.9	44.8–51.1	1360	83.8	81.6–85.7	764	50.1	47.2–52.9
Condition-related characteristics									
Functional screening questions									
Function	997	31.6	28.7–34.7	2428	66.2	63.3–69.0	1016	29.8	27.0–32.7
Prescription medications	2738	45.0	42.8–47.1	6398	86.6	85.3–87.9	3733	50.3	48.3–52.3
Service use	538	29.2	25.4–33.3	1372	64.8	61.1–68.4	642	31.5	27.9–35.4
Prescription medications and service use	1246	37.8	35.0–40.6	3288	82.3	80.0–84.3	1601	41.9	39.3–44.6
Intensity of need									
Usually/always	906	30.2	27.3–33.2	2272	64.1	61.2–67.0	924	28.9	26.2–31.8
Sometimes/never	4607	40.6	39.1–42.2	11 177	82.4	81.2–83.5	6059	45.1	43.6–46.6
Affected ability									
A lot	479	28.0	24.1–32.3	1178	62.8	59.0–66.4	463	27.9	24.1–32.1
Some	1379	34.2	31.5–36.9	3546	73.1	70.6–75.5	1599	34.4	32.0–36.9
A little	1197	36.8	34.0–39.6	3035	80.9	78.6–82.9	1539	40.3	37.6–42.9
Amount of school missed, d									
None	1088	37.7	34.6–40.8	2583	77.2	74.4–79.7	1403	41.5	38.6–44.4
1–5	2747	40.5	38.4–42.6	6542	79.6	77.9–81.1	3565	44.1	42.2–46.1
6–10	815	35.6	32.4–38.8	2095	77.7	74.8–80.4	1024	39.0	35.9–42.3
>10	757	35.1	31.6–38.7	1972	77.4	74.6–80.0	871	36.6	33.3–40.1
System-related characteristics									
Receives sufficient care coordination	1773	44.0	41.2–46.8	3947	82.9	80.9–84.8	2031	43.6	41.0–46.2
Satisfaction with care	3780	50.3	48.3–52.3	8180	88.5	87.2–89.6	4890	53.5	51.7–55.3
Medical home	3296	53.5	51.3–55.7	6979	89.0	87.8–90.1	4329	56.8	54.8–58.7
Adequate insurance coverage	3906	44.6	42.7–46.5	8762	83.0	81.6–84.3	5007	48.1	46.4–49.8
Screening through preventive dental and medical care	4062	41.8	40.1–43.6	9547	81.7	80.4–83.0	5226	45.9	44.2–47.5
Services are organized for easy access	5152	40.9	39.4–42.4	12 279	81.1	79.9–82.2	6595	44.3	42.8–45.7

^a Comprising all children who were between the ages of 12 and 17 years and either Hispanic, non-Hispanic white, or non-Hispanic black.

^b Anticipatory guidance is a composite variable based on 4 questions (*N* = 13 350 respondents).

^c *N* = 16 748 respondents.

^d “Received the services necessary to make transitions to all aspects of adult life” (ie, core outcome 6) is a composite variable based on 4 anticipatory guidance questions and 1 question about whether the child has been encouraged to take responsibility for his or her own health care (*N* = 15 679 respondents).

^e Comprising nonmetropolitan areas in Connecticut, Delaware, Hawaii, Massachusetts, Maryland, New Hampshire, Nevada, and Rhode Island.

^f Comprising metropolitan areas in Idaho, Maine, and Montana.

^g Comprising nonmetropolitan and metropolitan areas in Alaska, North Dakota, South Dakota, Vermont, and Wyoming.

Table 2 lists the distribution of CSHCN according to individual, condition-related, and system-related characteristics residing in high- (*n* = 4244), medium- (*n* = 10 989), and low- (*n* = 1643) performance states.

Table 3 lists the crude and adjusted factors associated with state performance for receipt of transition ser-

vices. Compared with non-Hispanic white CSHCN, Hispanic (aOR: 0.25 [95% CI: 0.17–0.37]) and non-Hispanic black (aOR: 0.44 [95% CI: 0.30–0.62]) CSHCN were less likely to reside in a high-performance state than in a low-performance state. Compared with CSHCN who had a medical home or adequate insurance coverage, CSHCN

who did not have a medical home or adequate insurance coverage were less likely to reside in a high-performance than in a low-performance state (aOR: 0.73 [95% CI: 0.57–0.95]; aOR 0.73 [95% CI: 0.58–0.93], respectively).

Compared with non-Hispanic white CSHCN, Hispanic CSHCN were also

TABLE 2 Individual, Condition-Related, and System-Related Characteristics of CSHCN Aged 12 to 17 Years (*N* = 16 876)^a Who Reside in High-, Medium-, and Low-Performance States With Regard to Transition Services^b: 2005–2006 National Survey of CSHCN

	High-Performance States (<i>N</i> = 4244)			Medium-Performance States (<i>N</i> = 10 989)			Low-Performance States (<i>N</i> = 1643)		
	<i>n</i>	Weighted %	95% CI	<i>n</i>	Weighted %	95% CI	<i>n</i>	Weighted %	95% CI
Individual characteristics									
Race/ethnicity									
Hispanic	186	5.5	4.3–6.9	1125	84.8	82.1–87.2	263	9.7	7.7–12.2
Non-Hispanic black	160	11.3	9.2–13.7	1180	77.2	74.1–80.0	410	11.6	9.5–14.0
Non-Hispanic white	3898	17.5	16.8–18.3	8684	75.1	74.1–76.0	970	7.4	6.7–8.1
Household education level									
Less than high school	100	9.8	7.1–13.3	546	82.2	77.6–86.0	107	8.1	5.5–11.7
High school	637	14.8	13.2–16.6	1746	75.3	72.9–77.5	301	9.9	8.3–11.8
More than high school	3497	15.8	15.2–16.6	8681	76.4	75.4–77.3	1231	7.8	7.2–8.5
Family household structure									
2-parent household (2 biological/adoptive parents)	2324	16.3	15.3–17.2	5615	76.9	75.6–78.1	666	6.9	6.1–7.8
2-parent household (2-parent step-families)	601	17.5	15.4–19.8	1396	72.5	69.4–75.3	233	10.0	8.0–12.4
1-parent household (mother only)	940	13.0	11.7–14.4	2912	77.6	76.7–79.3	548	9.5	8.2–10.9
Other family household structures	259	15.0	12.4–18.1	609	77.2	72.8–81.0	96	7.8	5.2–11.7
Family poverty level, % FPL									
0–99	386	12.4	10.6–14.4	1542	77.6	74.9–80.0	352	10.1	8.3–12.2
100–199	884	14.6	13.1–16.3	2111	75.5	73.1–77.6	356	9.9	8.4–11.8
200–399	1579	17.2	16.0–18.5	3611	75.1	73.5–76.7	470	7.7	6.6–8.9
≥400	1395	15.3	14.2–16.5	3725	77.9	76.4–79.4	465	6.8	5.8–7.9
Residence									
MSA	1828	14.3	13.5–15.1	6158	76.6	75.5–77.7	1178	9.1	8.3–9.9
Non-MSA	636	18.4	16.6–20.4	1470	71.6	69.3–73.7	465	10.0	8.7–11.5
<500 000 in nonmetropolitan areas ^c	375	6.9	6.2–7.6	2062	93.1	92.4–93.8	0	—	—
<500 000 in metropolitan areas ^d	376	43.0	40.3–45.8	702	57.0	54.2–59.7	0	—	—
<500 000 in nonmetropolitan and metropolitan areas ^e	1029	62.8	60.5–65.0	597	37.2	35.0–39.5	0	—	—
Condition-related characteristics									
Functional screening questions									
Function	838	13.6	12.2–15.1	2382	77.3	75.2–79.2	385	9.2	7.8–10.7
Prescription medications	1921	16.4	15.4–17.5	4766	76.4	74.9–77.7	631	7.2	6.2–8.3
Service use	458	13.6	11.7–15.8	1319	75.8	72.8–78.5	242	10.6	8.6–13.1
Prescription medications and service use	1027	15.4	14.0–17.0	2522	76.4	74.4–78.3	385	8.2	7.0–9.7
Intensity of need									
Usually/always	817	14.9	13.4–16.6	2272	75.4	73.2–77.5	392	9.7	8.3–11.3
Sometimes/never	3417	15.3	14.6–16.0	8677	76.8	75.8–77.7	1245	7.9	7.2–8.7
Affected ability									
A lot	435	14.9	12.8–17.3	1287	75.2	72.2–78.0	230	9.9	8.1–12.1
Some	1138	14.9	13.6–16.2	3033	77.1	75.4–78.8	487	8.0	6.9–9.3
A little	876	14.1	12.7–15.7	2436	77.6	75.5–79.6	353	8.3	6.8–10.1
Amount of school missed, d									
None	810	15.7	14.1–17.5	2109	75.7	73.3–77.8	332	8.7	7.2–10.5
1–5	2118	15.3	14.4–16.3	5179	77.1	75.8–78.4	705	7.6	6.7–8.6
6–10	634	15.0	13.2–16.9	1755	76.7	74.1–79.1	257	8.4	6.6–10.6
>10	602	14.8	13.0–16.7	1671	75.8	73.2–78.1	291	9.5	7.9–11.4
System-related characteristics									
Receives sufficient care coordination									
Yes	1199	15.8	14.4–17.2	2995	76.3	74.5–78.1	456	7.9	6.8–9.2
No	449	11.5	10.0–13.2	1542	77.5	74.9–79.9	310	11.0	9.1–13.3
Satisfied with care									
Yes	2477	16.9	15.9–17.9	5874	75.7	74.5–76.9	798	7.4	6.6–8.3
No	1663	13.2	12.3–14.2	4811	77.5	76.1–78.9	799	9.3	8.3–10.4
Medical home									
Yes	2143	17.5	16.4–18.6	4976	75.6	74.2–76.9	633	7.0	6.1–8.0
No	1944	13.5	12.6–14.4	5498	77.5	76.2–78.7	900	9.1	8.1–10.1
Adequate insurance coverage									
Yes	2778	16.3	15.4–17.2	6648	76.3	75.1–77.4	914	7.4	6.7–8.3
No	1409	13.5	12.5–14.6	4139	76.7	75.1–78.2	688	9.8	8.6–11.1
Screening through preventive dental and medical care									
Yes	2990	15.4	14.7–16.3	7486	77.1	76.1–78.2	1038	7.4	6.7–8.2
No	1231	14.7	13.5–16.0	3436	75.3	73.5–77.0	587	10.0	8.8–11.4
Services are organized for easy access									
Yes	3787	15.4	14.8–16.1	9678	76.6	75.7–77.5	1392	8.0	7.3–8.7
No	423	13.4	11.5–15.6	1192	75.6	72.6–78.4	231	11.0	9.0–13.4

^a Comprising all children who were between the ages of 12 and 17 years and either Hispanic, non-Hispanic white, or non-Hispanic black.

^b “Received the services necessary to make transitions to all aspects of adult life” (ie, core outcome 6) is a composite variable based on 4 anticipatory guidance questions and 1 question about whether the child has been encouraged to take responsibility for his or her own health care.

^c Comprising nonmetropolitan areas in Connecticut, Delaware, Hawaii, Massachusetts, Maryland, New Hampshire, Nevada, and Rhode Island.

^d Comprising metropolitan areas in Idaho, Maine, and Montana.

^e Comprising nonmetropolitan and metropolitan areas in Alaska, North Dakota, South Dakota, Vermont, and Wyoming.

less likely to reside in a medium-performance than in a low-performance state (aOR: 0.67 [95% CI: 0.50–0.90]). Compared with those who lived in a household with

2-parent biological/adoptive families, CSHCN who lived in 2-parent step-families were less likely to reside in a medium-performance than in a low-performance state (aOR:

0.64 [95% CI: 0.48–0.87]). In addition, CSHCN who did not have a medical home (aOR: 0.82 [95% CI: 0.65–1.04]) or adequate insurance (aOR: 0.83 [95% CI: 0.67–1.03]) were less likely

TABLE 3 Factors Associated With State Performance on Transition Services (High Versus Low Performance and Medium Versus Low Performance): 2005–2006 National Survey of CSHCN

	High-Performance States OR (95% CI) ^a		Medium-Performance States OR (95% CI) ^b	
	Logistic Regression, Crude	Logistic Regression, Adjusted Main Effects Only ^c	Logistic Regression, Crude	Logistic Regression, Adjusted Main Effects Only ^c
Individual characteristics				
Race/ethnicity				
Hispanic	0.24 (0.17–0.34)	0.25 (0.17–0.37)	0.86 (0.64–1.14)	0.87 (0.63–1.18)
Non-Hispanic black	0.41 (0.30–0.56)	0.44 (0.30–0.62)	0.66 (0.51–0.84)	0.67 (0.50–0.90)
Non-Hispanic white	Reference	Reference	Reference	Reference
Household education level				
Less than high school	0.60 (0.35–1.01)	1.44 (0.80–2.59)	1.04 (0.67–1.60)	1.84 (1.17–2.89)
High school	0.73 (0.57–0.95)	0.93 (0.69–1.24)	0.77 (0.61–0.98)	0.94 (0.72–1.23)
More than high school	Reference	Reference	Reference	Reference
Family household structure				
2-parent households (2-biological/adoptive parents)	Reference	Reference	Reference	Reference
2-parent households (2-parent step-families)	0.74 (0.55–1.00)	0.80 (0.58–1.10)	0.65 (0.49–0.86)	0.64 (0.48–0.87)
1-parent households (mother only)	0.58 (0.46–0.74)	0.78 (0.60–1.03)	0.73 (0.59–0.91)	0.83 (0.65–1.07)
All other family household structures	0.81 (0.50–1.33)	1.21 (0.71–2.07)	0.88 (0.55–1.41)	1.08 (0.64–1.81)
Family poverty level, % FPL				
0–99	0.54 (0.39–0.74)	1.04 (0.70–1.53)	0.67 (0.50–0.88)	0.96 (0.68–1.35)
100–199	0.65 (0.49–0.86)	1.03 (0.74–1.43)	0.66 (0.50–0.86)	0.81 (0.60–1.10)
200–399	0.98 (0.76–1.28)	1.27 (0.96–1.67)	0.85 (0.66–1.08)	1.01 (0.77–1.31)
≥400	Reference	Reference	Reference	Reference
Condition-related characteristics				
Functional screening criteria				
Function	0.65 (0.50–0.85)	^d	0.80 (0.62–1.02)	^d
Prescription medications	Reference	^d	Reference	^d
Service use	0.56 (0.41–0.78)	^d	0.67 (0.50–0.91)	^d
Prescription medications and service use	0.82 (0.63–1.07)	^d	0.88 (0.68–1.13)	^d
System-related characteristics				
Satisfaction with care				
Yes	Reference	Reference	Reference	Reference
No	0.62 (0.51–0.77)	0.88 (0.68–1.13)	0.82 (0.67–0.99)	1.06 (0.84–1.34)
Medical home				
Yes	Reference	Reference	Reference	Reference
No	0.59 (0.48–0.74)	0.73 (0.57–0.95)	0.79 (0.65–0.97)	0.82 (0.65–1.04)
Adequate insurance coverage				
Yes	Reference	Reference	Reference	Reference
No	0.63 (0.51–0.78)	0.73 (0.58–0.93)	0.76 (0.63–0.93)	0.83 (0.67–1.03)
Screening through preventive dental and medical care				
Yes	Reference	^d	Reference	^d
No	0.70 (0.57–0.88)	^d	0.72 (0.59–0.88)	^d
Services are organized for easy access				
Yes	Reference	^d	Reference	^d
No	0.63 (0.47–0.84)	^d	0.71 (0.55–0.93)	^d

^a High-performance states were those that were statistically significantly higher than the national average of 41.2% for receipt of transition services.

^b Medium-performance states were those that were statistically the same as the national average of 41.2% for receipt of transition services.

^c Potential confounders (race/ethnicity, household education level, family household structure, and family poverty level) were retained in final adjusted models.

^d Variables were not statically significant at $P \leq .10$ in final multivariable models.

to reside in a medium-performance than in a low-performance state; however, these results were not statistically significant.

Although we analyzed all 2-way interaction terms in the modeling process, only one 2-way interaction term (household education level × medical home) had a P value of $< .1$ (data not shown).

DISCUSSION

Receipt of services necessary to make transitions to all aspects of adult life is 1 of 6 important system indicators that mark successful state and national systems of care for CSHCN. Using NS-CSHCN data, we examined individual, condition-related, and system-related

characteristics to determine if these characteristics can explain state performance in the provision of transition services. After controlling for individual, condition-related, and system-related characteristics, we found that several factors were associated with high state performance on provision of transition services: race/ethnicity;

medical home; and insurance coverage. Race/ethnicity and family household structure seemed to be important characteristics of medium-performance states. More careful analysis needs to be conducted to determine if a true interaction exists between household education and establishing a medical home and how this finding should be interpreted. In addition, further analyses should take into account and adjust for multiple comparisons. A better understanding of the factors identified in this analysis and their association with the receipt of effective transition services can inform policy and program changes or development aimed at achieving transition-related service-system improvements within all states.

Our findings, that families of racial/ethnic minority CSHCN, lacking a medical home, and inadequate insurance coverage are associated with lower state performance, conform to usual patterns.^{19,30} These findings may indicate that underlying inequities in income, the distribution of wealth, health care access, and institutional racism are applicable to the systems of care for CSHCN as for children without special health care needs. This type of finding is not unique but has not been explored in depth among CSHCN.⁴⁴ CSHCN providers may need to consider offering additional or different types of services, recognizing that some families have fewer resources and may be less sure or less aggressive in negotiating complex and confusing systems of care. Health care providers must intensify efforts to establish meaningful, culturally competent partnerships with the families of CSHCN. Without meaningful provider and family partnerships, we can expect indicators of success to remain unacceptably low, even among the states that have shown better performance.

The significant associations of 2 system-related characteristics (CSHCN receive coordinated care in a medical home and CSHCN have adequate insurance coverage) with receipt of transition services supports the longstanding concept that a service system comprises elements that necessarily, by definition, interact and influence each other. For example, a true medical home would involve families in decision-making, monitor their satisfaction, and perform early childhood screening.⁴⁵ Similarly, uninsured families are unlikely to have a medical home, be satisfied with services, or experience ease in organizing needed services.

Because the study data are cross-sectional, it is not possible to determine a causal relationship between receipt of transition services and the factors that influence such services. The study is based on parental self-reports and may be influenced by recall bias and response bias. Although the sample size was adjusted for families without telephones, the sample may be biased in that families with telephones may not accurately reflect the experience of families without telephones or those with cellular telephones only.^{46,47} However, although cellular telephones are increasingly more common, households with young children tend to retain land lines.³⁵

In addition, although the study sample was limited to CSHCN between the ages of 12 and 17 years, parental reports about the receipt of transition services could be influenced by the child's age. Although all CSHCN should receive age- and stage-appropriate messages and information about transition services from their care providers on a regular basis, parents of CSHCN may have differential recall of this information. For example, parents of a younger child might not recall the

messages and information to the same extent as the parents of an older child.

Finally, we used a composite variable in place of numerous variables that make up transition services and its subcomponents. Although a composite variable provides a quick assessment of whether children within a state meet a specific parameter, a composite variable may "mask" information that would be useful in guiding program and policy development.

The results of this study have implications for both policy and practice. At the federal level, efforts that support the integration of the 6 system indicators in quality-improvement activities (particularly establishing a medical home and attaining or maintaining adequate insurance) are appropriate in light of this analysis and should continue. At the practice level, Healthy and Ready to Work (www.hrtw.org) is a national resource center through which Title V agencies and their stakeholders can share "promising practices in interagency collaboration, medical home, transition/youth, and family partnerships." This analysis also reinforces the roles and responsibilities traditionally fulfilled by state Title V CSHCN programs that relate to transition services. These programs are charged with (1) ensuring that families of CSHCN are decision-making partners in all levels of care and are satisfied with the care received, (2) providing coordinated care in a medical home, (3) ensuring that families of CSHCN have adequate insurance coverage, (4) ensuring that children are screened early and continuously for special health needs, and (5) organizing community-based services so that families can use them easily.

The ultimate goal, for CSHCN to receive necessary services for successful transition, will be achieved through partnered efforts of clinicians and

families. To move toward the provision of transition services as the standard of care within a practice, providers should consider using checklists and time lines, such as the one developed by the Institute for Community Inclusion at Children's Hospital Boston,⁴⁸ to organize and implement developmentally appropriate transition planning for CSHCN. Providers also may want to consider (1) alternative scheduling for well-child visits for CSHCN to minimize time away from work for low-income and single-parent families and (2) de-

veloping partnerships with school-based staff, such as school nurses and special education teachers who are working on similar issues with CSHCN with functional limitations, to avoid duplication, identify gaps, and coordinate efforts. Clinicians also may want to consider developing a practice-based parent advisory group to facilitate the exchange of information on topics such as insurance and accessing appropriate health care services for young adults with special health care needs.

CONCLUSIONS

This study reaffirms the complexity and difficulty of planning and performing effective systems-related quality improvement for transition services. Many factors influence the current experiences of CSHCN and their families. Meaningful system improvement becomes more likely with data that provide a foundational knowledge of the family experience and that help explain and guide policy recommendations and program development.

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Pediatrics 2009;124;S375

DOI: 10.1542/peds.2009-1255H

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