

Health Care System Factors Associated with Transition Preparation in Youth with Special Health Care Needs

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Abstract

The aim of this study was to assess: (1) the proportion of youth with special health care needs (YSHCN) with adequate transition preparation, (2) whether transition preparation differs by individual, condition-related and health care system-related factors, and (3) whether specific components of the medical home are associated with adequate transition preparation. The authors conducted a cross-sectional analysis of the 2009–2010 National Survey of Children with Special Health Care Needs, which surveyed a nationally representative sample of 17,114 parents of YSHCN ages 12 to 18 years. Adequate transition preparation was based on positive responses to questions about transition to an adult provider, changing health care needs, maintaining insurance coverage, and if providers encouraged YSHCN to take responsibility for health care needs. Weighted descriptive, bivariate and multivariate analyses were conducted to determine the association between patient and health care system factors and adequate transition preparation. Overall, 32.1% of YSHCN had adequate transition preparation. Older age, female sex, income $\leq 400\%$ of the poverty level, lack of medical complexity, and having shared decision making, family-centered care, and effective care coordination were associated with increased odds of transition preparation. The majority of YSHCN do not receive adequate transition preparation and younger, male adolescents with medical complexity were less likely to receive transition preparation. Different patterns of disparities were identified for each subcomponent measure of transition preparation, which may help target at-risk populations for specific services. Efforts to improve transition preparation should leverage specific components of the medical home including care coordination, shared decision making, and family-centered care.

Keywords: transition, youth with special health care needs, medical home, shared decision making, family-centered care

Introduction

CURRENTLY, 15%–20% OF YOUTH in the United States have health care needs that require care beyond what is typical for age.¹ Youth with special health care needs (YSHCN) are broadly defined as those who “have or are at increased risk of having a physical, mental, emotional or other type of health condition requiring a type or amount of health and related services beyond that required by children generally.”² Increasing numbers of YSHCN are transitioning to adult care but continue to face various barriers and difficulties in this process, which include delays, lack of care, and poor outcomes.^{3–6} The National Committee for Quality Assurance, Healthy People 2020, and several professional societies

have recommended early transition planning and service implementation to promote quality outcomes and avoid gaps in care.^{7–10} The Maternal and Child Health Bureau (MCHB) and the Title V Maternal and Child Health Block Grant Program have declared “transition preparation” as one of 6 core performance outcomes defining a high-performing system of care for YSHCN.⁷

Prior studies have demonstrated that 40% of YSHCN receive transition preparation with disparities related to sociodemographic, medical condition, and health-system factors including the presence of a medical home.^{7,11–13} Existing studies, however, defined the outcome of transition preparation based on whether the youth received transition preparation services if the parent thought the transition

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services were necessary. Little is known about the proportion of patients who receive transition preparation services regardless of whether the parent thought it was necessary and which factors are associated with this outcome. Although having a medical home is associated with transition preparation, it is unknown which of the 5 subcomponents (usual source of care, personal doctor or nurse, obtaining needed referrals, effective care coordination [ECC], and family-centered care [FCC]) are associated with adequate transition preparation. It also is unknown whether medical complexity and shared decision making (SDM) are associated with transition preparation.¹⁴

The aims of this study were: (1) to assess the proportion of YSHCN with adequate transition preparation, (2) to determine whether transition preparation differs by individual, condition-related, and health care system-related factors, and (3) to identify which components of the medical home are associated with transition preparation. Specifically, it examines the association between transition preparation and having SDM and the medical home, including its 5 individual subcomponent measures. The study team hypothesized that the majority of YSHCN do not receive adequate transition preparation and that disparities in transition preparation exist based on certain sociodemographic, condition, and health care system factors.

Methods

Data source

Data were used from the 2009–2010 National Survey of Children with Special Health Care Needs (NS-CSHCN), which was developed and funded by the MCHB and conducted by the Centers for Disease Control and Prevention. A total of 17,114 interviews were completed during 2009–2010 with a parent or legal guardian of youth ages 12–18 years.¹² Details of the survey methodology are presented elsewhere.^{15,16} The Stanford University Review Board found the study to be exempt from human subject review.

Primary outcome

A dichotomous variable was created to categorize whether the adolescent had adequate transition preparation. “Adequate transition preparation” was defined based on parent response to 4 survey items about whether their child’s medical provider discussed each of the following: (1) transfer to an adult provider, (2) adult health care needs, (3) obtaining or maintaining insurance coverage, and (4) taking responsibility for health care needs. In this study, respondents were considered to have “adequate” transition preparation only if the first 3 discussions took place and the child’s doctor “always” or “usually” encouraged the child to take responsibility for his or her health care needs.

Independent variables

Individual, condition-related and system-related variables were included in analyses based on previously demonstrated relationships to the transition outcome. The study team also chose to investigate the following additional variables based on associations with other unmet needs in YSHCN: parent education, medical complexity, individual subcomponents of the medical home, and SDM.^{14,17–21}

Youth and family characteristics

The following child and family sociodemographic variables were assessed: age (12–14 years, 15–17 years); sex; race/ethnicity (non-Hispanic white, non-Hispanic black, Hispanic, other); household language (English, not English); parent education (less than high school [HS] degree, HS degree, and greater than HS degree); household income (<100%, 100%–199%, 200%–399%, ≥400% of the federal poverty level [FPL]); and youth insurance status (private, public, both private and public, uninsured).

The following clinical characteristics were assessed: functional status (impact on daily activities); the presence of an emotional, behavioral, or developmental (EBD) condition; and medical complexity. Severe impact on daily activity was defined as the health condition “always” or “usually” affecting the youth’s daily activities. Medical complexity was as defined by Kuo et al: (1) a positive response to requiring more medical care on the NS-YSHCN screener; (2) a positive response to at least 3 of 4 remaining screener questions; and (3) at least 2 specialist visits in the previous year.¹⁴

Health care system-related characteristics

Finally, the study team analyzed the impact of the system-related variables of SDM and the medical home on transition preparation. SDM was defined by a “usually” or “always” response to how often in the past 12 months the child’s doctor or other health care providers: (1) discussed with the family a range of options to consider for their child’s treatment; (2) encouraged the family to ask questions or raise concerns; (3) made it easy to ask questions or raise concerns; and (4) considered and respected what treatment choices the family thought would work best for their child.

The medical home, as defined by the NS-YSHCN, is a composite variable of the following 5 components that are based on the medical home model described by the American Academy of Pediatrics (AAP): (1) having a usual source of care, (2) having a personal doctor or nurse, (3) obtaining all needed referrals for specialty care, (4) having ECC, and (5) receiving FCC. Parents must respond (“usually”/“always”) to all 5 components to meet the medical home outcome.²² For referrals, the “NA” category referred to children who did not need a referral or receive any services in the past 12 months. The AAP definition includes the following 7 components of the medical home, which are similar to those included in the Patient-Centered Medical Home model described by the Agency for Healthcare Research and Quality: accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective. The NS-YSHCN was able to operationalize only 5 of the 7 AAP components because of feasibility and methodologic constraints.^{22,23}

The ECC outcome is met if the family reports requiring more than 2 health-related medical, educational, or social services in the past 12 months and had a positive response to the following: (1) usually or always getting sufficient help coordinating care if needed, and being very satisfied with (2) the communication among doctors and other health care providers, and (3) the communication among doctors/health care providers and other programs such as early intervention or school. The NA category referred to YSHCN who did not

TABLE 1. CHARACTERISTICS OF YOUTH WITH SPECIAL HEALTH CARE NEEDS AGES 12 TO 18 YEARS:
UNITED STATES, 2009–2010 (N=17,114)

	<i>n</i>	<i>Weighted n</i>	<i>%</i>
Sex			
Male	9829	2527674	56.3
Female	7255	1963928	43.7
Age, years			
12–14	8313	2225741	49.4
15–17	8801	2275943	50.6
Race/ethnicity			
Non-Hispanic white	12588	2924993	65.0
Non-Hispanic black	1543	630737	14.0
Hispanic	1541	631766	14.0
All other ^a	1442	314189	7.0
Primary language in home			
English	16640	4253278	94.5
Not English	474	248406	5.5
Highest parental educational attainment			
Less than high school degree	851	486544	10.8
High school degree	2495	883666	19.6
Some college/college degree	13768	3131473	69.6
Poverty level			
0%–99% FPL ^b	2508	879359	19.5
100%–199% FPL	3162	953056	21.2
200%–399% FPL	5446	1301906	28.9
≥400% FPL	5998	1367363	30.4
Insurance status			
Private	10626	2461732	56.6
Public	4147	1396003	32.1
Both private and public	1122	314800	7.2
Uninsured	529	179853	4.1
Impact on activities			
Always/usually/a great deal affected	4050	1213375	27.0
Somewhat/moderately affected	6522	1716681	38.2
Never affected	6499	1559768	34.7
Emotional, behavioral, or developmental conditions			
Yes	5679	1608514	35.7
No	11435	2893170	64.3
Medical complexity			
Yes	894	232664	5.2
No	16220	4269020	94.8
Shared decision making			
Yes	12614	3157621	71.0
No	4305	1290896	29.0
Medical home			
Yes	7891	1861041	43.1
No	8620	2455396	56.9
Personal doctor or nurse			
Yes	16024	4162344	92.6
No	1061	332053	7.4
Usual sources of sick or well care			
Yes	15456	3991258	89.0
No	1593	491510	11.0
Family-centered care			
Yes	11538	2842611	64.2
No	5293	1573961	35.5
NA	48	14159	0.3
No problems with referrals			
Yes	4232	1054644	23.5
No	1030	343012	7.7
NA	11764	3081702	68.8

(continued)

TABLE 1. (CONTINUED)

	<i>n</i>	<i>Weighted n</i>	<i>%</i>
Effective care coordination			
Yes	7356	1839675	41.7
No	5134	1474509	33.4
NA	4356	1095085	24.8

^aAll other includes identification as Asian, Alaska Native, American Indian, Native Hawaiian, Pacific Islander, or mixed race.

^bFederal poverty level (FPL) for a family of 4 in 2009 was \$22,050.

NA, not applicable.

require the use of more than 2 health-related medical, educational, or social services in the past 12 months or if the family reported that no one provided help coordinating care and felt it was not necessary.

The FCC component, based on nationally endorsed and validated Consumer Assessment of Healthcare Providers and Systems items, is comprised of the following 5 questions asked of parents regarding whether their child's doctor: (1) spends enough time with them, (2) listens carefully, (3) is sensitive to the family's culture/values, (4) provides enough information, and (5) makes the family feel like partners. The NA category referred to YSHCN who did not visit any doctors or other health care providers in the past 12 months.

Data analysis

Descriptive statistics were used to report the characteristics of YSHCN and the proportion meeting the transition preparation outcome and the individual component measures (Table 1). Statistical analysis was conducted using SAS Enterprise Guide, version 6.1 (SAS Institute Inc., Cary, NC) and the SAS survey procedures to weight the data and account for the complex sample design. Multiple imputation techniques were conducted on missing data for poverty, race, and primary household language by the National Center of Health Statistics. $P < .05$ was considered to be statistically significant.

Descriptive and bivariate analysis methods using χ^2 tests of independence (Table 2) were performed to evaluate the relationship between selected independent variables and the transition outcome, including its subcomponents. In 2 phases, multiple logistic regression models (Tables 3 and 4) were used to calculate adjusted odds ratios (AORs) to identify independent predictors of not meeting the transition outcome and its subcomponents. The outcome was defined as not meeting transition preparation to maintain consistency with previous studies.¹² In both phases, the models included the described sociodemographic and condition-related characteristics as covariates. Phase 1 incorporated the system characteristics of SDM and having a medical home while the phase 2 analysis included SDM and the 5 medical home subcomponents.

Results

The study population included a total of 17,114 YSHCN. Their sociodemographic and health characteristics are displayed in Table 2. Based on the definition, 32.1% of YSHCN had adequate transition preparation. The majority had discussed taking responsibility for self-care, but a mi-

nority had discussed changing health care needs, maintaining health insurance coverage, or shifting to an adult provider (Table 2).

Several factors were associated with transition preparation and its individual component measures in bivariate analyses (Table 2). Older youth and those with SDM, FCC, and ECC were more likely to have adequate transition preparation including the individual subcomponents. Female youth and those without an EBD condition were more likely to meet the transition preparation outcome and all of the subcomponent measures except for discussing the shift to an adult provider. Lower impact of health on activities and lack of medical complexity were associated with adequate transition preparation and encouraging youth to take responsibility for self-care. Patterns of significant associations were found but were not consistent across transition measures for the following variables: primary household language, parent education, poverty level, and insurance status.

The AOR for the associations between the socio-demographic and condition-related factors and transition preparation including its component measures are reported in Table 3. Younger age (12–14 years) was associated with a higher likelihood of not meeting the transition outcome (AOR: 1.66, 95% confidence interval [CI]: 1.47–1.89) and its component measures. Males had a higher likelihood of inadequate transition services and not discussing adult health care needs and taking responsibility for self-care. Parent high school education and all poverty levels $\leq 400\%$ of the FPL had a higher likelihood of adequate transition; however, this trend was not consistent across individual component measures. Medically-complex YSHCN had a higher likelihood of inadequate transition services and not being encouraged to take responsibility for self-care but a lower likelihood of discussing shifting to adult care and changing health care needs (Table 3).

The AOR for the association between the health care system factors and transition preparation and its component measures are displayed in Table 4. Not having a medical home was associated with a higher likelihood of inadequate transition preparation (AOR: 1.18, 95% CI: 1.03–1.35) and not having discussions about health insurance and encouragement of responsibility for self-care. In phase 2, not having SDM was associated with a higher likelihood of not meeting the transition outcome and its component measures with the strongest impact on responsibility for self care (Table 4). Not having ECC was associated with a higher likelihood of not meeting the transition outcome and its component measures. Not having FCC was also significantly associated with a higher odds of inadequate transition preparation and not having discussions related to changing adult health care needs

TABLE 2. PROPORTION OF YOUTH WITH SPECIAL HEALTH CARE NEEDS, AGES 12 TO 18, MEETING THE TRANSITION OUTCOME AND INDIVIDUAL COMPONENT MEASURES, ACCORDING TO SELECTED SOCIODEMOGRAPHIC AND HEALTH CARE SYSTEM FACTORS: UNITED STATES, 2009–2010

	<i>Doctor or other health care provider discussed shift to adult provider (n = 10,309)</i>	<i>Doctor or other health care provider discussed adult health care needs (n = 17,002)</i>	<i>Anyone discussed health insurance (n = 17,053)</i>	<i>Doctor or other health care provider usually/always encourages youth to take responsibility when needed (n = 17,050)</i>	<i>Overall outcome: youth receives services necessary to make transition to adult life (n = 16,613)</i>
	% (SE) ^a	% (SE)	% (SE)	% (SE)	% (SE)
Total	20.9 (0.7)	44.1 (0.7)	23.2 (0.6)	78.0 (0.6)	32.1 (0.6)
Sex					
Male	20.0 (0.9)	40.2 (0.9)***	22.1 (0.7)*	76.0 (0.8)***	30.5 (0.8)**
Female	22.2 (1.2)	48.9 (1.1)	24.6 (1.0)	80.6 (0.9)	34.1 (1.0)
Age, years					
12–14	14.1 (0.8)***	40.2 (1.0)***	19.4 (0.8)***	76.0 (0.9)**	26.9 (0.9)***
15–17	28.5 (1.2)	47.8 (1.0)	27.0 (0.9)	79.9 (0.8)	37.2 (0.9)
Race/ethnicity					
Non-Hispanic white	20.0 (0.8)*	44.2 (0.8)	22.2 (0.6)**	79.9 (2.1)***	32.7 (0.7)
Non-Hispanic black	21.3 (2.0)	43.1 (2.0)	29.2 (2.0)	72.3 (1.8)	28.6 (2.2)
Hispanic	21.0 (2.4)	42.3 (2.4)	20.8 (2.1)	74.9 (2.1)	31.6 (1.9)
All other ^b	29.1 (3.3)	48.0 (2.6)	25.4 (2.5)	78.0 (1.9)	34.3 (2.6)
Primary language in home					
English	20.9 (0.7)	44.5 (0.7)*	23.4 (0.6)	78.5 (0.6)*	32.3 (0.6)
Not English	22.3 (4.3)	36.0 (4.0)	20.8 (3.8)	69.5 (3.8)	28.6 (3.9)
Highest parental education					
Less than high school	20.8 (3.1)	42.4 (2.8)	26.5 (2.7)	72.8 (2.4)**	35.0 (2.7)**
High school	20.9 (1.8)	44.3 (1.7)	24.3 (1.4)	75.0 (1.6)	37.1 (1.6)
Some college/college	21.0 (0.8)	44.3 (0.7)	22.4 (0.7)	79.6 (0.6)	30.2 (0.7)
Poverty level					
0%–99% FPL ^c	21.7 (1.9)	45.4 (1.7)	24.0 (1.6)	71.2 (1.5)***	35.1 (1.7)***
100%–199% FPL	20.6 (1.8)	42.0 (1.6)	23.4 (1.5)	75.8 (1.4)	36.4 (1.6)
200%–399% FPL	19.7 (1.2)	44.3 (1.2)	23.3 (1.0)	79.4 (1.1)	31.6 (1.1)
≥400% FPL	21.8 (1.2)	44.5 (1.1)	22.5 (1.0)	82.5 (0.9)	27.6 (1.0)
Insurance status					
Private	12.4 (0.6)	25.7 (0.6)***	22.7 (0.7)***	47.0 (0.7)***	31.7 (0.8)
Public	6.1 (0.5)	13.6 (0.5)	22.4 (1.2)	23.2 (0.7)	33.8 (1.3)
Both private and public	1.7 (0.2)	3.6 (0.3)	34.8 (2.6)	4.9 (0.3)	27.2 (2.5)
Uninsured	0.5 (0.1)	1.3 (0.2)	17.3 (4.5)	2.8 (0.3)	31.4 (4.1)
Impact on activities					
Always/usually/a great deal affected	21.3 (1.5)	42.1 (1.4)	23.2 (1.3)	63.5 (1.4)***	25.5 (1.2)***
Somewhat/moderately affected	21.7 (1.2)	45.2 (1.1)	22.7 (0.9)	81.0 (0.9)	34.6 (1.1)
Never affected	19.8 (1.2)	44.3 (1.1)	23.9 (1.0)	86.0 (0.8)	34.4 (1.1)

(continued)

TABLE 2. (CONTINUED)

	<i>Doctor or other health care provider discussed shift to adult provider (n = 10,309)</i>	<i>Doctor or other health care provider discussed adult health care needs (n = 17,002)</i>	<i>Anyone discussed health insurance (n = 17,053)</i>	<i>Doctor or other health care provider usually/always encourages youth to take responsibility when needed (n = 17,050)</i>	<i>Overall outcome: youth receives services necessary to make transition to adult life (n = 16,613)</i>
	% (SE) ^a	% (SE)	% (SE)	% (SE)	% (SE)
Emotional, behavioral, or developmental conditions					
Yes	19.9 (1.2)	39.8 (1.1)***	21.0 (1.0)**	68.1 (1.1)***	27.8 (1.1)***
No	21.5 (0.9)	46.4 (0.9)	24.5 (0.8)	83.5 (0.7)	34.4 (0.8)
Medical complexity					
Yes	27.3 (3.1)*	46.3 (2.9)	24.0 (2.5)	56.7 (3.0)***	17.6 (2.1)***
No	20.5 (0.7)	43.9 (0.7)	23.2 (0.6)	79.1 (0.6)	32.9 (0.7)
Shared decision making					
Yes	22.8 (0.9)***	51.1 (0.8)***	26.1 (0.7)***	87.4 (0.6)***	36.2 (0.7)***
No	16.5 (1.3)	27.8 (1.2)	16.8 (1.1)	56.1 (1.4)	22.3 (1.1)
Medical home					
Yes	22.0 (1.1)	50.1 (1.0)***	26.4 (0.9)***	89.5 (0.6)***	36.6 (0.9)***
No	20.6 (1.0)	40.3 (1.0)	21.1 (0.9)	70.0 (0.9)	28.6 (0.9)
Personal doctor or nurse					
Yes	20.9 (0.7)	44.2 (0.7)	23.3 (0.6)	78.8 (0.6)***	31.9 (0.7)
No	21.2 (3.3)	43.1 (2.9)	22.3 (2.6)	68.0 (2.7)	34.6 (0.7)
Usual sources of sick or well care					
Yes	20.5 (0.7)	44.1 (0.7)*	23.3 (0.6)	78.7 (0.6)***	31.7 (0.7)
No	25.1 (2.7)	43.7 (2.3)	22.0 (2.0)	72.3 (2.0)	34.5 (2.3)
Family-centered care					
Yes	22.3 (0.9)*	49.5 (0.8)***	25.3 (0.7)***	86.6 (0.6)***	35.6 (0.8)***
No	18.8 (1.3)	35.3 (1.2)	20.0 (1.1)	63.6 (1.2)	26.0 (1.1)
NA	11.4 (9.8)	28.2 (9.9)	11.0 (6.3)	21.3 (7.4)	14.0 (6.5)
No problems with referrals					
Yes	20.9 (1.4)**	51.5 (1.0)*	21.7 (1.1)	79.5 (1.1)***	31.9 (1.3)
No	20.8 (2.8)	35.9 (1.2)	21.6 (3.1)	64.1 (2.8)	26.9 (2.7)
NA	20.9 (0.9)	43.6 (1.4)	24.0 (0.7)	79.1 (0.7)	32.8 (0.8)
Effective care coordination					
Yes	24.7 (1.2)***	51.5 (1.0)***	26.3 (0.9)***	85.9 (0.7)***	35.2 (1.0)***
No	18.7 (1.2)	35.9 (1.2)	17.9 (1.0)	65.1 (1.2)	24.0 (1.1)
NA	18.3 (1.4)	43.6 (1.4)	25.4 (1.3)	83.0 (1.1)	37.4 (1.3)

^a χ^2 tests of independence. * $P < .05$, ** $P < .01$, *** $P < .001$.

^bAll other includes identification as Asian, Alaska Native, American Indian, Native Hawaiian, Pacific Islander, or mixed race.

^cFederal poverty level (FPL) for a family of 4 in 2009 was \$22,050.

NA, not applicable; SE, standard error.

TABLE 3. ADJUSTED ODDS RATIO OF YOUTH WITH SPECIAL HEALTH CARE NEEDS, AGES 12 TO 18, NOT MEETING THE TRANSITION PREPARATION OUTCOME, ACCORDING TO SELECTED INDIVIDUAL AND CONDITION-RELATED FACTORS: UNITED STATES, 2009–2010

	<i>Components, adjusted OR (CI)^a</i>				
	<i>Did not discuss shift to adult provider</i>	<i>Did not discuss adult health care needs</i>	<i>Did not discuss health insurance</i>	<i>Youth not usually/always encouraged to take responsibility</i>	<i>Youth did not receive adequate transition preparation</i>
Sex					
Female	1.00	1.00	1.00	1.00	1.00
Male	1.16 (0.97–1.38)	1.40 (1.25–1.58)***	1.13 (0.99–1.30)	1.24 (1.06–1.46)**	1.14 (1.01–1.30)*
Age, years					
12–14	2.51 (2.10–3.01)***	1.41 (1.25–1.58)***	1.61 (1.39–1.85)***	1.29 (1.09–1.51)**	1.66 (1.47–1.89)***
15–17	1.00	1.00	1.00	1.00	1.00
Race/ethnicity					
Non-Hispanic white	1.00	1.00	1.00	1.00	1.00
Non-Hispanic black	0.84 (0.63–1.12)	0.92 (0.76–1.12)	0.63 (0.50–0.79)***	1.24 (0.97–1.58)	1.13 (0.92–1.39)
Hispanic	0.99 (0.69–1.40)	0.87 (0.68–1.10)	1.09 (0.81–1.45)	0.90 (0.66–1.22)	1.27 (0.97–1.65)
All other ^b	0.64 (0.45–0.89)**	0.81 (0.65–1.01)	0.84 (0.64–1.09)	1.01 (0.78–1.32)	0.94 (0.74–1.19)
Primary language in home					
English	1.00	1.00	1.00	1.00	1.00
Not English	1.18 (0.67–2.10)	1.26 (0.81–1.96)	1.13 (0.67–1.92)	1.19 (0.72–1.96)	1.14 (0.73–1.19)
Highest parental educational attainment					
Less than high school degree	0.99 (0.61–1.62)	0.99 (0.76–1.01)	0.70 (0.52–0.96)*	0.86 (0.62–1.18)	0.81 (0.61–1.07)
High school degree	1.03 (0.78–1.34)	0.97 (0.82–1.15)	0.86 (0.71–1.04)	1.02 (0.81–1.30)	0.83 (0.70–0.98)*
Some college/college degree	1.00	1.00	1.00	1.00	1.00
Poverty level					
0%–99% FPL ^c	0.85 (0.56–1.28)	0.65 (0.50–0.83)***	0.93 (0.70–1.23)	0.82 (0.61–1.11)	0.47 (0.36–0.61)***
100%–199% FPL	0.88 (0.64–1.20)	0.84 (0.69–1.02)	0.92 (0.73–1.16)	0.83 (0.64–1.07)	0.50 (0.41–0.61)***
200%–399% FPL	1.05 (0.84–1.31)	0.87 (0.76–1.01)	0.91 (0.77–1.07)	0.92 (0.75–1.12)	0.72 (0.62–0.84)***
≥400% FPL	1.00	1.00	1.00	1.00	1.00
Insurance status					
Private	1.00	1.00	1.00	1.00	1.00
Public	1.13 (0.82–1.56)	1.19 (0.98–1.43)	1.10 (0.88–1.38)	1.28 (1.00–1.63)	1.15 (0.94–1.42)
Both private and public	0.91 (0.64–1.29)	0.89 (0.70–1.13)	0.54 (0.41–0.71)***	1.57 (1.16–2.11)**	1.31 (0.99–1.72)
Uninsured	1.60 (0.88–2.89)	1.75 (1.20–2.56)**	1.27 (0.70–2.29)	1.28 (0.81–2.02)	1.01 (0.68–1.50)
Impact on activities					
Always/usually/a great deal affected	0.82 (0.63–1.06)	0.85 (0.71–1.01)	0.85 (0.69–1.04)	1.83 (1.45–2.31)***	1.17 (0.97–1.40)
Somewhat/moderately affected	0.86 (0.69–1.06)	0.89 (0.77–1.02)	1.01 (0.86–1.19)	1.00 (0.82–1.23)	0.93 (0.80–1.07)
Never affected	1.00	1.00	1.00	1.00	1.00
Emotional, behavioral, or developmental conditions					
Yes	1.15 (0.94–1.42)	1.17 (1.02–1.35)*	1.13 (0.95–1.34)	1.31 (1.09–1.58)**	1.10 (0.95–1.28)
No	1.00	1.00	1.00	1.00	1.00
Medically complex					
Yes	0.67 (0.47–0.95)*	0.72 (0.54–0.96)*	0.87 (0.63–1.20)	1.71 (1.27–2.30)***	1.69 (1.22–2.35)**
No	1.00	1.00	1.00	1.00	1.00

^aAdjusted for all other covariates in Tables 3 and 4. * $P < .05$, ** $P < .01$, *** $P < .001$.

^bAll other includes identification as Asian, Alaska Native, American Indian, Native Hawaiian, Pacific Islander, or mixed race.

^cFederal poverty level (FPL) for a family of 4 in 2009 was \$22,050.

CI, confidence interval; OR, odds ratio.

TABLE 4. ADJUSTED ODDS RATIO OF YOUTH WITH SPECIAL HEALTH CARE NEEDS, AGES 12 TO 18, NOT MEETING THE ADEQUATE TRANSITION PREPARATION OUTCOME, ACCORDING TO SELECTED HEALTH CARE SYSTEM-RELATED FACTORS: UNITED STATES, 2009–2010

		<i>Components, adjusted OR (CI)^a</i>									
		<i>Did not discuss shift to adult provider</i>		<i>Did not discuss adult health care needs</i>		<i>Did not discuss health insurance</i>		<i>Youth not usually/always encouraged to take responsibility</i>		<i>Youth did not receive adequate transition preparation</i>	
		<i>Phase 1</i>	<i>Phase 2</i>	<i>Phase 1</i>	<i>Phase 2</i>	<i>Phase 1</i>	<i>Phase 2</i>	<i>Phase 1</i>	<i>Phase 2</i>	<i>Phase 1</i>	<i>Phase 2</i>
SDM											
Yes	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
No	1.55 (1.23–1.95)***	1.41 (1.11–1.79)**	2.72 (2.34–3.17)***	2.43 (1.07–2.85)***	1.65 (1.35–2.01)***	1.58 (1.28–1.96)***	4.03 (3.40–4.78)***	3.42 (2.89–4.10)***	1.93 (1.63–2.29)***	1.73 (1.44–2.07)***	
Medical home											
Yes	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
No	0.97 (0.80–1.17)	1.13 (1.00–1.29)	1.21 (1.04–1.42)*	1.91 (1.59–2.31)***	1.18 (1.03–1.35)*						
Personal doctor or nurse											
Yes	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
No	0.95 (0.65–1.41)	0.92 (0.71–1.19)	1.10 (0.81–1.48)								
Usual sources of sick or well care											
Yes	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
No	0.61 (0.44–0.83)**	0.84 (0.69–1.03)	1.01 (0.79–1.29)								
Family-centered care											
Yes	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
No	1.05 (0.83–1.33)	1.18 (1.02–1.36)*	1.04 (0.86–1.25)								
NA	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00
No referral problems											
Yes	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
No	0.91 (0.61–1.35)	1.06 (0.80–1.40)	0.78 (0.53–1.14)								
NA	0.93 (0.75–1.15)	0.99 (0.86–1.14)	0.87 (0.74–1.03)								
Effective care coordination											
Yes	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
No	1.36 (1.08–1.72)**	1.38 (1.19–1.61)***	1.44 (1.20–1.73)***								
NA	1.39 (1.08–1.78)*	1.22 (1.05–1.42)	1.00 (0.84–1.19)								

^aAdjusted for sex, age, race/ethnicity, primary household language, parental education, income, insurance status, impact on activities, presence of an emotional, behavioral or developmental condition, medical complexity. * $P < .05$, ** $P < .01$, *** $P < .001$.

CI, confidence interval; NA, not applicable; OR, odds ratio; SDM, shared decision making.

and taking responsibility for self-care. Lacking a usual source of care was associated with a higher likelihood of not discussing the shift to an adult provider. Not having a need for care coordination was significantly associated with a higher likelihood of not discussing the shift to an adult provider and adult health care needs.

Discussion

A minority (32%) of YSHCN have the necessary discussions with a health care provider to achieve adequate transition preparation, with rates for meeting the individual components of transition ranging from 21% (discussing the shift to an adult provider) to 78% (encouraging responsibility for self-care). Disparities in transition preparation existed that differed by subcomponent measure. YSHCN who were between the ages of 12–14, male, and medically complex, and those without SDM, FCC, and ECC were at the greatest risk for inadequate transition services.

This study represents the first to analyze the transition outcome as it relates to the receipt of transition preparation services and associated factors. Compared to 40% of YSHCN who met the national transition outcome definition, 32% had adequate transition preparation in this study.¹² Regarding the individual transition components, the study team found a 12.8% to 23% lower rate of meeting the individual transition components based on the definition versus the national outcome.¹² As expected, the team found the same rate for taking responsibility for self-care as this did not incorporate parent perceived need for the discussion. This difference suggests that fewer youth may be receiving transition services than previously thought though youth reports would be useful to substantiate these results.

Compared to prior studies, present study data showed that lower income YSHCN had increased rather than decreased odds of transition preparation and no effect of race, ethnicity, or insurance status on receipt of transition services.^{3,7,12} These results may be explained by the overreporting of transition discussions related to a social desirability or acquiescence bias, which has been shown to be more common in socially disadvantaged groups.²⁴ However, this also may reflect a positive effect of federal and state policy to increase transition readiness in lower income youth or that higher income youth are receiving inadequate preparation.²⁵ An additional hypothesis is that many families have a lower income because of reducing work hours to care for their chronically ill children, which may help promote health care engagement and greater transition services.²⁶

This study also was the first to analyze the effect of SDM and the individual components of the medical home, which significantly increased the likelihood of transition preparation. In a post hoc analysis to determine an effect of these variables on the NS-YSHCN transition core outcome, SDM, FCC, and ECC all proved to be significant, highlighting their importance in transition preparation regardless of perceived need by the parent (data not shown). This supports prior research that these components can reduce unmet needs of YSHCN and improve overall health status and costs of care.^{18,27–30}

It was interesting to note the disparities specifically associated with encouraging responsibility for self-care. This discussion relates to increasing self-management, which is

an important means to promote better health outcomes.³¹ Though the majority of YSHCN did have this discussion, this analysis showed that YSHCN who were the most medically complex, had an EBD condition, and whose condition had the most severe impact had a significantly lower likelihood of discussing responsibility for self-care. More efforts need to focus on applying effective strategies such as SDM to address these existing disparities.^{32–34} Using peer networks is one such approach that could increase SDM and self-management in these vulnerable youth and lead to improvements in quality of care and long-term health.^{34,35}

These results have implications for how to improve transition preparation from a systems perspective. A focused effort on the evaluation and implementation of SDM, FCC, and care coordination at an earlier age may be necessary to move transition preparation forward; based on these data, it is possible that providers are waiting to initiate discussions until these youth are closer to the time of actual transfer. There is a clear need to identify best practices and existing models that have advanced these significant and modifiable system factors. They reflect having providers and/or systems that encourage more time, partnership with and understanding of the family, assistance with care coordination, and general high-quality interactions that might promote better transition services.

Previous policy changes at the federal level have offered promise to advance transition care by targeting the system factors associated with adequate services. The Affordable Care Act has insured the adolescent young adult population at much higher numbers and offered chronic disease management as an essential health benefit.^{36,37} MCHB guidance aims to increase the number of children with special health care needs who have a medical home that is “accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective” as well as to increase the percentage of YSHCN who receive transition services. Funding distributed to the states through the Title V Maternal and Child Health Services Block Grant Program has encouraged innovation toward providing family-centered and community-based coordinated care. The majority of states (32) chose transition as a performance measure with 23 (71%) states identifying the importance of a medical home and the specific components of care coordination and family engagement as priorities.²⁵ Restructuring payment models, such as the recent new fee schedules proposed by the Centers for Medicare & Medicaid Services for transitional care management, improves reimbursement for time and effort to coordinate services for the most complex patients and may help to promote the quality of care associated with these system factors and possibly reduce costs.^{21,28,38,39} It will be important to see whether certain states or youth show notable changes in transition preparation or health status after incorporating these interventions.

This study has several limitations. The survey is cross-sectional so there is a limited ability to make causal conclusions from the results. There also is a low response rate and a reliance on parent report, which may lead to reporting bias, especially when focusing on outcomes related to the 12–17-year-old age group. The survey would benefit from the inclusion of a youth report regarding transition outcomes. Furthermore, reliance on self-report contributes to

recall bias and subjective interpretation that differs by parent. However, it is important to solicit the perspectives of families and young adults regarding the need for and receipt of transition preparation. Therefore, self-report regarding these topics is important to facilitate the transition process and determine areas and populations with unmet needs.

In summary, a majority of YSHCN did not receive adequate transition preparation in 2009–2010. This study identified significant individual, condition-, and health care system-related disparities in transition-care preparation, which may help to identify at-risk populations. This study further suggests that the most effective strategies to improve transition preparedness may need to increase SDM, and to leverage the FCC and care-coordination components of the medical home.

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