

Transition Planning Among US Youth With and Without Special Health Care Needs

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abstract

BACKGROUND: Researchers have shown that most youth with special health care needs (YSHCN) are not receiving guidance on planning for health care transition. This study examines current transition planning among US youth with and without special health care needs (SHCN).

METHODS: The 2016 National Survey of Children's Health is nationally representative and includes 20 708 youth (12–17 years old). Parents and/or caregivers were asked if transition planning occurred, based on the following elements: (1) doctor or other health care provider (HCP) discussed the eventual shift to an HCP who cares for adults, (2) an HCP actively worked with youth to gain self-care skills or understand changes in health care at age 18, and (3) youth had time alone with an HCP during the last preventive visit. Sociodemographic and health system characteristics were assessed for associations with transition planning.

RESULTS: Nationally, 17% of YSHCN and 14% of youth without SHCN met the overall transition measure. Older age (15–17 years) was the only sociodemographic factor associated with meeting the overall transition measure and individual elements for YSHCN and youth without SHCN. Other sociodemographic characteristics associated with transition planning differed among the 2 populations. Receipt of care coordination and a written plan was associated with transition planning for YSHCN.

CONCLUSIONS: This study reveals that few youth with and without SHCN receive transition planning support. It underscores the need for HCPs to work with youth independently and in collaboration with parents and/or caregivers throughout adolescence to gain self-care skills and prepare for adult-focused care.

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Dr Lebrun-Harris conducted all the data analysis, drafted the methods and results sections, and prepared Tables 1 through 4; Ms McManus drafted the introduction, and with the other authors, drafted the discussion and conclusion sections; Ms Ilango participated in drafting the introduction and discussion sections; Ms Cyr, Ms McLellan, and Drs Mann and White participated in drafting the introduction, discussion, and conclusion sections; and all authors contributed to the conceptualization of the study and provided critical review of the manuscript, approved the final manuscript as submitted, and agree to be accountable for all aspects of the work.

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WHAT'S KNOWN ON THIS SUBJECT: Past national studies have revealed that most youth with special health care needs (YSHCN) did not receive guidance on transition planning. Lack of transition planning was associated with several sociodemographic and health factors.

WHAT THIS STUDY ADDS: With this nationally representative study, we present results on new measures of transition planning among YSHCN as well as youth without special health care needs. The relationship between transition planning and various health system characteristics among YSHCN is also examined.

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Adolescence is recognized as a critical developmental period of transition from childhood to adulthood.^{1,2} Twenty-five million youth in the United States are between the ages of 12 and 17,³ and 5 million have a special health care need (SHCN).⁴ Since the early 2000s, health professional organizations and public health agencies have articulated the importance of health care transition (hereafter referred to as “transition”) planning, especially for youth with special health care needs (YSHCN).^{5–13} More recently, in 2011, the American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), and American College of Physicians reached a consensus regarding specific transition steps for all youth.¹⁴ These steps call for health care providers (HCPs) to address (1) transition planning by engaging youth and their parents and/or caregivers in assessing and developing self-care skills for an adult model of care at age 18, (2) transfer of care by assisting youth in identifying adult HCPs and ensuring a smooth handoff with updated medical records, and (3) integration into adult care by orienting new young adult patients about the practice’s approach and offering self-care assessment and skill building. In addition, in 2015, the Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB) Title V Services Block Grant Program introduced its transition performance measure calling for an increased percentage of all youth to receive services necessary to transition to adult health care.¹⁵

Published literature continues to reveal persistent barriers impeding transition progress for YSHCN.¹⁶ Lack of structured transition intervention is associated with adverse consequences, which include discontinuity of care,^{17,18} difficulties with treatment adherence,¹⁹ excess morbidity,²⁰ dissatisfaction

and worry,^{21–23} and preventable emergency department and hospital visits.²⁴ The few studies on transition among youth without special health care needs (non-YSHCN) reveal they are less involved in completing medical tasks than peers with SHCNs. Additionally, HCPs are no more likely to discuss future goals with YSHCN than with non-YSHCN.^{25,26}

With this article, we present nationally representative data on transition planning among youth with and, for the first time, without SHCNs from the 2016 National Survey of Children’s Health (NSCH).²⁷ The NSCH transition questions align with the AAP, AAFP, and American College of Physicians clinical report (hereafter referred to as “clinical report”)¹⁴ and published theoretical models, which are used to recommend HCP communication and engagement of youth and parents throughout adolescence.^{28–31} We address the following 3 questions in this study: (1) What are the rates of transition planning among youth with and without SHCNs? (2) What differences exist in transition planning by sociodemographic factors? (3) What is the relationship between receipt of transition planning for YSHCN and various health system characteristics?

METHODS

In this exploratory analysis, we estimated the proportion of US youth, ages 12 through 17, meeting the overall transition planning measure as well as the 3 individual elements, stratified by SHCN status. We also examined sociodemographic and health system characteristics potentially associated with transition planning.

Data Source

Data came from the 2016 NSCH, a cross-sectional survey of noninstitutionalized children and youth, ages 0 through 17

years, in the 50 US states and the District of Columbia.²⁷ The survey provides state-level and nationally representative estimates of key indicators of child and family health. With funding and direction from HRSA MCHB, the US Census Bureau conducted the 2016 NSCH from June 2016 to February 2017, using address-based sampling. Invitation letters were sent to randomly selected households to participate in the internet survey; nonresponders received multiple mailings, including a paper instrument to complete and return by mail. The survey was available in English and Spanish.

The total NSCH sample was 50 212 children and youth, including 20 708 youth ages 12 through 17 years. The overall weighted response rate was 40.7%. The survey completion rate (proportion of households with children and youth who completed a detailed topical questionnaire) was 69.7%. Sampling weights were adjusted to account for nonresponse and reduce the magnitude of bias.³² Poststratification adjustment was conducted to ensure that sociodemographic subgroups were appropriately represented. Additional information regarding survey methodology and response rates is available elsewhere.^{27,33,34} Secondary data were used in this study, which was therefore exempt from institutional review board review.

Measures

The primary dependent variable of interest was transition planning, a composite measure based on responses to 4 survey items. These items were selected to align with the Title V performance measure³⁵ and the clinical report.¹⁴ Parents and/or caregivers of youth answered questions used to evaluate whether the following had taken place: (1) a doctor (or other HCP) discussed transition to an HCP who treats adults, (2) an HCP actively worked

to help youth understand health care changes at age 18, (3) an HCP actively worked with youth to gain self-care skills, and (4) youth had time alone with an HCP at his or her last preventive visit. Each item was dichotomously coded (1 = yes; 0 = no). The first item (“discussed shift to adult provider”) was asked only for youth who saw an HCP who treats only children; youth who saw an HCP who treats both children and adults were also coded as “yes.” The next 2 survey items were combined and called “provider active work with youth” and coded affirmatively if respondents answered “yes” to either item. The final item (“youth time alone with provider”) was asked only for youth with a preventive visit in the past 12 months; youth with no preventive visit were coded as “no” on this element.

The overall transition measure was calculated on the basis of available information for each of the 3 elements (ie, discussed shift to adult provider, provider actively worked with youth, youth time alone with provider). The overall measure was also a dichotomous variable (1 = met all 3 elements; 0 = met <3 elements). Items that were skipped or left blank were not included in the calculation. With this coding approach, we preserved sample size, reduced potential bias, and ensured consistency with HRSA MCHB’s preferred methods for coding multi-item performance measures for Title V.

SHCN status was based on responses to the Children with Special Health Care Needs Screener, a 5-item tool designed to identify children by assessing functional limitations, prescription medication use, elevated service use or need, use of specialized therapies, and ongoing emotional, developmental, or behavioral conditions.³⁶

Several variables were assessed for associations with transition planning, informed by previous analyses of

transition.^{37–39} Sociodemographic factors included sex, age, race and/or ethnicity, insurance type, highest household education, and federal poverty level (FPL). FPL was calculated as the ratio of total family income and the family poverty threshold. Respondents reported total family income for the previous year (2015) and number of household members; family poverty threshold was derived from the Census Bureau’s poverty thresholds, which vary by family size and number of related children <18 years old.³⁴ After examination, it was determined that potential multicollinearity between household education and FPL was not a concern for our adjusted models.

For YSHCN, health system characteristics were also examined because of their relevance for this population. These included having a personal doctor and/or nurse, usual source of care when sick, family-centered care, problems getting referrals, care coordination, medical home, and receipt of a written plan, which align with the Standards of Care for Children and YSHCN.⁴⁰ Personal doctor and/or nurse and usual source of care when sick were dichotomous measures, each based on a single survey item. Family-centered care was dichotomized on the basis of whether respondents affirmatively reported on the following 5 items: HCPs spend enough time with the child, listen carefully, show sensitivity to the family’s values and/or customs, provide information concerning child, and help the parent and/or caregiver feel like a partner in the child’s care. Problems getting referrals were dichotomized on the basis of whether respondents reported it was a “small problem” or “big problem” to get a referral when needed. Care coordination was based on whether respondents reported being “very satisfied” on the following 3 items: communication among the child’s

HCPs, receipt of help when needed with arranging and/or coordinating the child’s health care, and the HCPs communication with school, child care provider, or special education program. Medical home was a composite measure based on the combination of the 5 previous components.⁴¹ Finally, a written plan was based on a single survey item used to ask whether the youth’s HCPs had worked with the family to create a written plan to meet the youth’s health goals and needs.

Data Analyses

We estimated the proportion of US youth, ages 12 through 17 years, meeting the overall transition measure and its 3 individual elements, stratified by SHCN status to reflect Title V’s interest in tracking transition planning separately for each subpopulation. Bivariate analyses were used to examine unadjusted rates of transition planning within each subpopulation by characteristics of interest; these analyses were used to provide descriptive percentages of overall transition planning and individual elements. We conducted χ^2 tests of independence with design-based F statistics to compare unadjusted rates of transition planning with sociodemographic characteristics of interest, separately for YSHCN and non-YSHCN.

Multivariable logistic regression models were used to assess the independent relationship between the transition measure (and each individual element) and various sociodemographic correlates. The models were used to provide adjusted relative prevalence rates to understand the likelihood that youth with characteristics of interest will receive various transition planning elements relative to youth in meaningful reference groups while holding other correlates constant. Separate models were conducted for YSHCN and non-YSHCN. Estimates are

reported as adjusted prevalence rate ratios (PRRs) and 95% confidence intervals (CIs) comparing the association between each covariate and the likelihood of meeting the transition measure.^{42–44} Finally, bivariate analyses for YSHCN were conducted to compare unadjusted rates of transition planning according to the presence or absence of various health system characteristics.

The following demographic variables were imputed for raking during weighting procedures and preserving sample size: sex (0.1% missing), race (0.3%), ethnicity (0.6%), and FPL (18.6%). The demographic variables were imputed by using hot-deck imputation, whereas FPL was multiply imputed by using regression imputation; a multiple imputation file containing 6 FPL implicates was used to calculate estimates with correct SEs.⁴⁵ All analyses were weighted on the basis of the survey's sampling design to produce nationally representative estimates and were conducted by using Stata SE 15 (Stata Corp, College Station, TX).⁴⁶

RESULTS

Table 1 shows the sociodemographic characteristics of the total sample, stratified by SHCN status. There were racial and/or ethnic and insurance differences between YSHCN and non-YSHCN, namely a higher proportion of non-Hispanic white youth and privately insured youth were among YSHCN compared with non-YSHCN.

In 2016, 17% of YSHCN and 14% of non-YSHCN received all 3 elements of the overall transition measure (Table 2). The proportions of youth meeting individual transition elements were considerably higher. Forty-one percent of YSHCN discussed the shift to an adult HCP, 69% had an HCP who actively worked with them to gain self-care skills or understand changes in health care at age 18, and 44% had time alone with their HCP during their last preventive

TABLE 1 Sociodemographic Characteristics of Youth With and Without SHCNs, Ages 12–17: United States, 2016

	Overall, <i>n</i> = 20 708	YSHCN, <i>n</i> = 5862	Non-YSHCN, <i>n</i> = 14 846	<i>P</i>
	% (SE)	% (SE)	% (SE)	
Sex				
Male	51.1 (0.8)	53.7 (1.4)	50.2 (0.9)	.05
Female	48.9 (0.8)	46.3 (1.4)	49.8 (0.9)	—
Age, y				
12–14	49.7 (0.8)	48.7 (1.4)	50.0 (0.9)	.42
15–17	50.3 (0.8)	51.3 (1.4)	50.0 (0.9)	—
Race and/or ethnicity				
White, non-Hispanic	53.2 (0.8)	57.6 (1.5)	51.8 (0.9)	<.001
Black or African American, non-Hispanic	13.7 (0.6)	15.8 (1.3)	13.1 (0.7)	—
Hispanic	23.5 (0.9)	19.1 (1.5)	24.9 (1.0)	—
Other, non-Hispanic	9.6 (0.4)	7.5 (0.5)	10.3 (0.5)	—
Insurance type				
Private only	60.2 (0.8)	52.3 (1.4)	25.9 (1.0)	<.001
Public only	28.4 (0.8)	35.9 (1.5)	62.8 (1.0)	—
Private and public	4.8 (0.4)	7.9 (0.9)	3.8 (0.4)	—
Uninsured	6.6 (0.5)	3.8 (0.5)	7.5 (0.6)	—
Highest household education level				
Less than high school	10.6 (0.8)	8.9 (1.3)	11.1 (1.0)	.33
High school diploma or GED	21.1 (0.7)	21.2 (1.3)	21.1 (0.8)	—
Some college and/or technical school	23.3 (0.6)	24.6 (1.2)	22.8 (0.8)	—
College degree or higher	45.0 (0.8)	45.3 (1.4)	44.9 (0.9)	—
Household poverty level, % FPL				
<100	20.5 (0.9)	21.6 (1.3)	20.1 (1.0)	.53
100–199	21.9 (0.8)	22.3 (1.4)	21.8 (1.0)	—
200–399	26.3 (0.7)	25.1 (1.3)	26.7 (0.9)	—
≥400	31.3 (0.7)	31.0 (1.2)	31.4 (0.8)	—

Data source: United States Census Bureau. NSCH. Available at: <https://www.census.gov/programs-surveys/nsch/data.html>. Accessed August 8, 2018. GED, general education diploma; FPL, federal poverty level; —, not applicable.

visit. YSHCN were more likely than non-YSHCN to meet the individual elements for active work to gain skills and/or understand health care changes and time alone with HCP, but non-YSHCN were more likely than YSHCN to discuss the shift to an adult provider ($P < .001$ for all). In adjusted analyses, older age (15–17 years) was the only sociodemographic factor associated with increased prevalence of meeting the overall transition measure and individual elements for both YSHCN and non-YSHCN (Table 3).

Among YSHCN, no covariate besides age was associated with the overall transition measure as well as all 3

individual elements (Table 3). Other factors were associated with meeting individual elements for YSHCN. YSHCN from college-educated households had an 18% decreased prevalence of HCPs discussing the shift to adult providers compared with YSHCN from high school–educated households. Non-Hispanic black or African American YSHCN had a 17% increased prevalence of HCPs actively working with them to gain skills or understand changes in health care at age 18, compared with non-Hispanic white YSHCN. Uninsured YSHCN had a 24% decreased prevalence compared with privately insured YSHCN in regard to HCPs who actively worked with them

TABLE 2 Proportion of Youth With and Without SHCNs, Ages 12–17, Meeting the Overall Health Care Transition Planning Measure and Individual Elements by Selected Sociodemographic Factors: United States, 2016

	Overall Transition Measure: Youth Receives Services To Make Transition to Adult Health Care				Doctor or Other HCP Discussed Shift to Adult Provider When Needed				Doctor or Other HCP Actively Worked With Youth To Gain Skills or Understand Changes in Health Care				Youth Had Time Alone With Their Doctor or Other HCP at Last Preventive Checkup			
	YSHCN, n = 5786	Non-YSHCN, n = 14 677	YSHCN, n = 5706	Non-YSHCN, n = 14 364	YSHCN, n = 5288	Non-YSHCN, n = 12 689	YSHCN, n = 5713	Non-YSHCN, n = 14 462	YSHCN, n = 5288	Non-YSHCN, n = 12 689	YSHCN, n = 5713	Non-YSHCN, n = 14 462	YSHCN, n = 5288	Non-YSHCN, n = 12 689	YSHCN, n = 5713	Non-YSHCN, n = 14 462
	% (SE)	P	% (SE)	P	% (SE)	P	% (SE)	P	% (SE)	P	% (SE)	P	% (SE)	P	% (SE)	P
Total	16.5 (1.0)	—	14.2 (0.7) ^a	—	41.2 (1.4)	—	52.2 (1.0) ^b	—	68.6 (1.4)	—	55.3 (1.0) ^b	—	44.4 (1.4)	—	36.7 (0.9) ^b	—
Sex																
Male	14.4 (1.2)	.02	14.6 (0.9)	.61	38.5 (1.8)	.04	51.2 (1.3)	.26	65.4 (2.0)	.02	54.5 (1.4)	.45	42.4 (1.8)	.13	40.0 (1.3)	<.001
Female	19.0 (1.6)	—	13.9 (0.9)	—	44.3 (2.2)	—	53.3 (1.4)	—	72.3 (2.1)	—	56.0 (1.5)	—	46.6 (2.1)	—	33.4 (1.2)	—
Age, y																
12–14	9.6 (1.3)	<.001	10.0 (0.8)	<.001	32.6 (2.1)	<.001	43.8 (1.4)	<.001	65.6 (2.1)	.04	52.7 (1.4)	.01	35.5 (2.0)	<.001	30.5 (1.2)	<.001
15–17	23.1 (1.4)	—	18.4 (1.0)	—	49.4 (1.9)	—	60.8 (1.3)	—	71.7 (2.0)	—	58.0 (1.4)	—	53.0 (1.9)	—	42.9 (1.3)	—
Race and/or ethnicity																
White, non-Hispanic	16.4 (0.9)	.16	14.6 (0.6)	.80	41.3 (1.4)	.99	51.1 (0.9)	.04	66.9 (1.5)	.54	52.3 (1.0)	.01	46.0 (1.4)	.33	39.6 (0.9)	.02
Black or African American, non-Hispanic	21.0 (3.7)	—	13.1 (1.7)	—	41.5 (4.4)	—	14.6 (2.5)	—	72.8 (5.0)	—	63.4 (3.0)	—	42.9 (4.4)	—	36.4 (2.9)	—
Hispanic	12.6 (2.6)	—	14.5 (2.1)	—	40.6 (4.7)	—	47.7 (2.9)	—	70.6 (4.4)	—	55.8 (2.9)	—	39.2 (4.5)	—	32.5 (2.5)	—
Other, non-Hispanic	17.9 (2.7)	—	13.1 (1.4)	—	41.2 (3.4)	—	51.7 (2.7)	—	68.3 (3.3)	—	58.5 (2.8)	—	47.7 (3.4)	—	32.6 (2.4)	—
Insurance type																
Private only	17.7 (1.2)	.19	14.1 (0.7)	.13	40.3 (1.5)	.08	48.3 (1.0)	<.001	70.2 (1.4)	.29	54.6 (1.1)	.73	49.2 (1.5)	.01	40.1 (1.0)	<.001
Public only	13.5 (1.6)	—	14.9 (1.7)	—	40.0 (2.8)	—	55.5 (2.3)	—	70.3 (2.6)	—	56.9 (2.5)	—	39.3 (2.7)	—	34.9 (2.2)	—
Private and public	15.0 (4.7)	—	15.2 (2.8)	—	43.3 (6.0)	—	55.8 (5.6)	—	62.4 (6.3)	—	59.1 (6.4)	—	38.4 (5.6)	—	30.5 (4.4)	—
Uninsured	23.8 (6.1)	—	8.6 (1.9)	—	59.7 (5.9)	—	67.1 (4.2)	—	60.1 (6.7)	—	52.9 (4.9)	—	40.5 (6.3)	—	19.3 (2.8)	—
Highest household education level																
Less than high school	13.2 (5.1)	.80	15.7 (3.9)	.68	45.9 (8.3)	.33	72.0 (4.1)	<.001	76.1 (7.6)	.56	59.5 (5.1)	.24	41.0 (8.0)	.03	25.6 (4.3)	<.001
High school diploma or GED	16.2 (2.3)	—	13.1 (1.3)	—	45.4 (3.6)	—	61.6 (2.3)	—	66.1 (4.2)	—	53.7 (2.5)	—	37.1 (3.4)	—	30.0 (2.1)	—
Some college/technical school	16.3 (1.7)	—	15.0 (1.3)	—	40.9 (2.6)	—	52.7 (1.9)	—	67.6 (2.8)	—	58.3 (2.0)	—	40.9 (2.6)	—	37.4 (1.8)	—
College degree or higher	17.1 (1.3)	—	13.7 (0.7)	—	37.9 (1.6)	—	42.4 (1.0)	—	68.0 (1.5)	—	53.2 (1.2)	—	50.1 (1.6)	—	42.4 (1.1)	—
Household poverty level, % FPL																
<100 FPL	17.8 (2.8)	.07	15.0 (2.3)	.45	45.6 (3.8)	.32	59.4 (3.1)	<.001	68.0 (4.1)	.76	56.0 (3.3)	.74	39.8 (3.6)	.001	31.0 (2.8)	<.001
100–199	11.7 (1.9)	—	13.4 (1.4)	—	40.4 (3.5)	—	57.3 (2.5)	—	67.4 (4.0)	—	57.3 (2.7)	—	40.0 (3.6)	—	31.7 (2.3)	—
200–399	17.4 (2.2)	—	13.1 (1.0)	—	41.8 (2.9)	—	52.2 (1.8)	—	71.1 (2.5)	—	54.2 (1.8)	—	42.1 (2.9)	—	37.1 (1.7)	—
≥400	18.4 (1.6)	—	15.1 (0.9)	—	38.2 (1.8)	—	44.1 (1.2)	—	67.9 (2.0)	—	54.2 (1.3)	—	52.5 (2.0)	—	43.4 (1.3)	—

Data source: United States Census Bureau, NSCH. Available at: <https://www.census.gov/programs-surveys/nsch/data.html>. Accessed August 8, 2018. GED, general education diploma; FPL, federal poverty level; —, not applicable.

^a P = .05 for χ^2 test used to compare YSHCN with non-YSHCN.

^b P < .001 for χ^2 test used to compare YSHCN with non-YSHCN.

TABLE 3 Adjusted PRRs for Youth With and Without SHCNs, Ages 12–17, Meeting the Overall Health Care Transition Planning Measure and Individual Elements by Selected Sociodemographic Factors: United States, 2016

	Overall Transition Measure: Youth Receives Services To Make Transition to Adult Health Care				Doctor or Other HCP Discussed Shift to Adult Provider When Needed				Doctor or Other HCP Actively Worked With Youth To Gain Skills or Understand Changes in Health Care				Youth Had Time Alone With Their Doctor or Other HCP at Last Preventive Checkup			
	YSHCN, n = 5588		Non-YSHCN, n = 14 094		YSHCN, n = 5525		Non-YSHCN, n = 13 832		YSHCN, n = 5124		Non-YSHCN, n = 12 238		YSHCN, n = 5521		Non-YSHCN, n = 13 897	
	PRR	95% CI	PRR	95% CI	PRR	95% CI	PRR	95% CI	PRR	95% CI	PRR	95% CI	PRR	95% CI	PRR	95% CI
Sex																
Male	0.83	0.64–1.02	1.09	0.89–1.28	0.91	0.79–1.03	0.94	0.87–1.01	0.93	0.86–1.00	0.97	0.90–1.03	0.96	0.84–1.07	1.21	1.09–1.32
Female	1.00	—	1.00	—	1.00	—	1.00	—	1.00	—	1.00	—	1.00	—	1.00	—
Age, y																
12–14	1.00	—	1.00	—	1.00	—	1.00	—	1.00	—	1.00	—	1.00	—	1.00	—
15–17	2.39	1.73–3.05	1.87	1.49–2.25	1.52	1.30–1.75	1.38	1.28–1.49	1.11	1.03–1.20	1.10	1.02–1.18	1.50	1.30–1.69	1.46	1.31–1.61
Race and/or ethnicity																
White, non-Hispanic	1.00	—	1.00	—	1.00	—	1.00	—	1.00	—	1.00	—	1.00	—	1.00	—
Black or African American, non-Hispanic	1.40	0.89–1.91	0.84	0.58–1.10	0.98	0.77–1.20	0.86	0.73–0.98	1.17	1.06–1.28	1.20	1.07–1.33	1.05	0.84–1.25	0.95	0.79–1.12
Hispanic	0.89	0.45–1.33	0.91	0.64–1.18	0.96	0.71–1.20	0.92	0.81–1.03	1.07	0.94–1.21	1.04	0.92–1.16	0.91	0.71–1.11	0.97	0.82–1.11
Other, non-Hispanic	1.15	0.76–1.54	1.01	0.78–1.24	1.01	0.84–1.19	1.02	0.91–1.12	1.04	0.93–1.15	1.11	1.00–1.23	1.06	0.88–1.24	0.87	0.74–1.00
Insurance type																
Private only	1.00	—	1.00	—	1.00	—	1.00	—	1.00	—	1.00	—	1.00	—	1.00	—
Public only	0.77	0.48–1.06	1.15	0.85–1.44	0.86	0.65–1.06	0.96	0.84–1.08	0.94	0.83–1.04	1.01	0.89–1.13	0.92	0.75–1.10	1.11	0.94–1.28
Private and public	0.88	0.38–1.38	1.23	0.71–1.75	1.00	0.74–1.26	1.02	0.79–1.26	0.83	0.65–1.01	1.04	0.79–1.29	0.85	0.60–1.10	0.94	0.66–1.22
Uninsured	1.23	0.50–1.95	0.59	0.29–0.89	1.25	0.92–1.57	1.12	0.92–1.31	0.76	0.57–0.96	0.90	0.72–1.08	0.86	0.58–1.13	0.60	0.42–0.78
Highest household education level																
Less than high school	0.91	0.20–1.61	1.10	0.52–1.67	1.01	0.61–1.42	1.15	0.98–1.32	1.11	0.90–1.33	1.11	0.89–1.33	1.12	0.67–1.56	0.83	0.53–1.12
High school diploma or GED	1.00	—	1.00	—	1.00	—	1.00	—	1.00	—	1.00	—	1.00	—	1.00	—
Some college and/or technical school	1.04	0.67–1.40	1.10	0.82–1.38	0.88	0.71–1.05	0.84	0.75–0.93	0.98	0.86–1.10	1.07	0.95–1.20	1.07	0.85–1.29	1.20	1.00–1.39
College degree or higher	0.99	0.63–1.34	0.98	0.75–1.21	0.82	0.65–0.99	0.70	0.62–0.77	0.96	0.85–1.08	0.99	0.88–1.10	1.22	0.98–1.46	1.31	1.10–1.52
Household poverty level, % FPL																
<100	1.22	0.70–1.74	0.87	0.59–1.15	1.28	0.95–1.61	1.07	0.89–1.25	1.02	0.87–1.17	0.95	0.78–1.12	0.94	0.72–1.16	0.83	0.64–1.01
100–199	0.77	0.42–1.12	0.82	0.58–1.07	1.07	0.80–1.34	1.13	1.00–1.27	0.98	0.83–1.13	0.99	0.87–1.10	0.91	0.72–1.10	0.82	0.68–0.95
200–399	1.05	0.70–1.40	0.86	0.68–1.03	1.11	0.90–1.31	1.11	1.01–1.20	1.06	0.95–1.16	0.97	0.89–1.13	0.87	0.73–1.01	0.90	0.80–1.01
≥400	1.00	—	1.00	—	1.00	—	1.00	—	1.00	—	1.00	—	1.00	—	1.00	—

Data source: United States Census Bureau. NSCH. Available at: <https://www.census.gov/programs-surveys/nsch/data.html>. Accessed August 8, 2018. GED, general education diploma; FPL, federal poverty level; —, not applicable.

TABLE 4 Proportion of YSHCN, Ages 12–17, Meeting the Overall Health Care Transition Planning Measure and Individual Elements by Health System Characteristics

	Overall Transition Measure: Youth Receives Services To Make Transition to Adult Health Care, <i>n</i> = 5786		Doctor or Other HCP Discussed Shift to Adult Provider When Needed, <i>n</i> = 5706		Doctor or Other HCP Actively Worked With Youth To Gain Skills or Understand Changes in Health Care, <i>n</i> = 5288		Youth Had Time Alone With Their Doctor or Other HCP at Last Preventive Checkup, <i>n</i> = 5713	
	% (SE)	<i>P</i>	% (SE)	<i>P</i>	% (SE)	<i>P</i>	% (SE)	<i>P</i>
Personal doctor or nurse								
Yes	17.0 (1.1)	.25	39.4 (1.4)	.04	70.7 (1.4)	.02	45.5 (1.5)	.17
No	14.2 (2.0)	—	48.2 (4.1)	—	59.8 (4.5)	—	39.6 (3.9)	—
Usual source of care when sick								
Yes	16.6 (1.0)	.68	39.2 (1.4)	.01	69.0 (1.4)	.70	46.0 (1.4)	.06
No	15.3 (2.8)	—	51.2 (4.7)	—	67.0 (5.2)	—	37.1 (4.3)	—
Family-centered care								
Yes	18.9 (1.1)	.06	39.8 (1.4)	.62	73.6 (1.2)	<.001	50.3 (1.4)	.01
No	12.4 (2.8)	—	42.3 (4.8)	—	44.8 (5.0)	—	37.4 (4.4)	—
Problems getting referrals								
Yes	15.9 (3.4)	.31	36.6 (4.8)	.37	59.0 (5.4)	.003	40.0 (5.0)	.13
No	20.2 (2.2)	—	41.6 (2.8)	—	75.4 (2.4)	—	48.9 (2.8)	—
Care coordination								
Yes	20.4 (1.5)	<.001	39.0 (1.9)	.84	76.6 (2.0)	<.001	49.4 (2.1)	.04
No	10.5 (1.1)	—	39.7 (2.5)	—	52.8 (2.7)	—	42.8 (2.5)	—
Medical home ^a								
Yes	18.3 (1.3)	.10	38.3 (1.7)	.06	76.4 (1.4)	<.001	48.0 (1.8)	.02
No	15.1 (1.4)	—	43.5 (2.1)	—	62.3 (2.3)	—	41.5 (2.1)	—
Written plan								
Yes	22.9 (2.7)	.003	43.4 (3.2)	.48	88.7 (2.3)	<.001	53.2 (3.3)	.004
No	15.2 (1.0)	—	40.9 (1.6)	—	64.5 (1.6)	—	42.7 (1.5)	—

Data source: United States Census Bureau. NSCH. Available at: <https://www.census.gov/programs-surveys/nsch/data.html>. Accessed August 8, 2018. —, not applicable.

^a Medical home is defined as having (1) a personal doctor or nurse, (2) a usual source of care when sick, (3) family-centered care, (4) no problems getting referrals, and (5) care coordination.

to gain skills or understand changes in health care.

Among non-YSHCN, being uninsured was associated with a 41% decreased prevalence of the overall transition measure compared with being privately insured (Table 3). When examining individual elements for non-YSHCN, we found that a different pattern of sociodemographic factors influenced transition planning compared with YSHCN. Having a parent and/or caregiver with some college or a college degree was associated with a decreased prevalence of HCPs discussing the shift to adult HCPs, compared with having only a high school diploma. In addition, youth from households between 200% and 399% FPL had an increased prevalence of discussing the shift to adult HCPs, compared with those from households at or

above 400% FPL. Non-Hispanic black or African American non-YSHCN had a decreased prevalence of discussing the shift to adult HCPs compared with their non-Hispanic white counterparts; however, they had increased prevalence of working with HCPs to gain skills or understand changes in health care. Factors associated with increased prevalence of youth having time alone with their HCP at their last preventive visit included male sex and having a parent and/or caregiver with a college degree. Factors associated with a decreased prevalence of having time alone included lack of insurance and FPL levels between 100% and 199%.

Associations with transition planning were examined for YSHCN on the basis of the presence of various health system characteristics (Table 4).

A greater proportion of YSHCN who received care coordination and a written plan met the criteria for the overall transition measure compared with those who did not. Having a personal doctor or nurse was associated with greater proportions of YSHCN actively working with their HCP to build skills or understand health care changes at age 18 but smaller proportions discussing the shift to adult HCPs. Having a usual source of care was also associated with smaller proportions of YSHCN discussing the shift to adult HCPs. Receiving family-centered care, care coordination support, care in a medical home, and having a written plan were each positively associated with 2 of the 3 elements (active work to gain skills or understand changes in health at 18 and time alone with an HCP).

DISCUSSION

This study reveals a low level of transition planning among US youth (17% for YSHCN and 14% for non-YSHCN). Over half of youth (especially those with SHCNs) actively work with their HCPs to gain self-care skills or understand changes in health care at age 18. Other aspects of transition planning are less commonly addressed, including having time alone with the HCP during preventive care visits and discussing the eventual shift to HCPs who treat adults. Moreover, although youth ages 15 through 17 have higher rates of transition planning than their younger peers (ages 12–14), only 23% of YSHCN and 18% of non-YSHCN ages 15 to 17 are receiving transition planning guidance. Importantly, for YSHCN, receipt of care coordination and a written plan of care was associated with meeting the overall transition measure. The 2016 NSCH results cannot be directly compared with previous surveys because of changes in survey methods and transition measure elements.³³

The finding that older age for both YSHCN and non-YSHCN was positively associated with the overall transition planning measure is not surprising because most pediatricians believe transition planning should begin at age 18⁴⁷ or between ages 18 and 20.⁴⁸ For YSHCN, the finding that care coordination was significantly associated with overall transition performance is also not unexpected. Researchers have shown that care coordination is associated with improved transition procedures, and when pediatric practices have a designated individual responsible for care coordination, they are more likely to have a written transition plan.⁴⁷ Current measures of transition planning may not adequately predict youth engagement in care or successful transfer to adult care.⁴⁹

With our study, we found that non-Hispanic black or African American youth were more likely to work with their HCP to gain skills and understand changes at 18, compared with non-Hispanic white youth but were also less likely to discuss the shift to an adult HCP. Possible explanations for these findings are less clear. Perhaps a larger proportion of non-Hispanic black or African American youth are seeking care without parents present and are more likely to be seen by clinics that care for all ages; therefore, they do not need to transfer to a different HCP.⁵⁰ The findings that youth from households with lower incomes and youth from households with less education were more likely to discuss the shift to an adult HCP compared with their counterparts from higher income, higher education households are also difficult to explain. More research is needed to shed light on these unexpected findings.

To increase transition performance, HCPs who care for youth should consider how to incorporate transition as part of routine health care visits, including time alone to prepare youth for managing their own health and health care. This alone time, recommended by the AAP and AAFP,^{51,52} increases adherence to and engagement in care and likelihood of sharing health risks with HCPs.^{53,54} Transition planning should include discussions about privacy and consent changes at age 18 and the age when transfer to an adult HCP is recommended. It is important for HCPs to engage parents and/or caregivers with youth starting at age 12 to plan for transition, including assessing transition readiness and encouraging parent and/or caregiver involvement in building independent health care skills among their youth.¹⁴ Given the importance of health insurance coverage in terms of use of health care and receipt of transition planning, HCPs should work with youth and families to

identify coverage options. Having a structured transition intervention, such as the 6 Core Elements of Health Care Transition,⁵⁵ aligned with the clinical report,¹⁴ improves adherence to care, health literacy, consumer satisfaction, and lower emergency department and hospital visits.⁵⁶

This study is limited by several factors. The NSCH is a cross-sectional study; therefore, correlations can be established but not directionality of those relationships. Information is obtained from parents and/or caregivers, not youth, which may inadvertently over- or underestimate the extent to which transition planning took place, considering parents and/or caregivers may not have been present during medical appointments. Youth and young adults are key partners in this transition discussion; however, there are currently no national surveys that ask transition questions directly to them.

The transition planning items were not part of a psychometrically validated tool; however, they were selected to align with HRSA MCHB's revised transition performance measure used by state Title V programs, which 37 states and jurisdictions have selected to prioritize and report data annually.⁵⁷ The revised measure was selected through a consensus process with a multidisciplinary workgroup of internal and external stakeholders. The workgroup concurred that the items selected reflect key elements of successful transition planning for both youth with and without SHCNs, although admittedly not all elements. Another potential limitation involves the analytic decision to count patients as achieving the overall transition measure if they met just 1 or 2 of the transition elements but were missing the rest. Sensitivity analyses indicated there was minimal impact on the weighted estimate regardless of whether a data preservation approach or complete-case approach

was employed. Another limitation is the greater proportion of disadvantaged youth (eg, low income, low education) who had parents who reported “Don’t Know” to the questions on active work to gain skills or understand changes. These responses were treated as missing in calculating the overall transition measure; thus, these youth met the overall measure on the basis of fewer elements. In addition, youth with no preventive visits in the past year were coded as not having time alone with a provider in the past year, which disproportionately affected uninsured youth who were less likely to have a past-year preventive visit. Thus, study results may be impacted by these various coding decisions. Finally, small sample sizes impeded analysis of the transition measure by state and among YSHCN with specific health conditions. Future iterations of the NSCH can be used to enable pooling of multiple years

of data to allow analyses of smaller subpopulations.

CONCLUSIONS

Findings from this study underscore the urgent need for HCPs to work with youth independently and in collaboration with their parents and/or caregivers throughout the adolescent years to improve transition planning. An important part of this developmental trajectory includes discussions about the eventual transfer to an HCP who cares for adults, explicit guidance about gaining self-care skills, what turning 18 means for health care (eg, health decisions, privacy), and time alone with the HCP. Further research is needed to perform confirmatory analyses with a priori hypotheses to corroborate or reject the observed associations found in this study. In addition, we recommend further efforts at the national level to better

understand transition experiences of youth and young adults.

ABBREVIATIONS

AAFP: American Academy of Family Physicians
AAP: American Academy of Pediatrics
CI: confidence interval
FPL: federal poverty level
HCP: health care provider
HRSA: Health Resources and Services Administration
MCHB: Maternal and Child Health Bureau
Non-YSHCN: youth without special health care needs
NSCH: National Survey of Children’s Health
PRR: prevalence rate ratio
SHCN: special health care need
YSHCN: youth with special health care needs

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Transition Planning Among US Youth With and Without Special Health Care Needs

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Transition Planning Among US Youth With and Without Special Health Care Needs

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