## **RESEARCH ARTICLE**

# WILEY

# Readiness for transition to adult health care among US adolescents, 2016-2020

Mackenzie Mulkey<sup>1</sup> | A. Brooke Baggett<sup>2,3</sup> | Dmitry Tumin<sup>2</sup>

<sup>1</sup>Department of Anthropology, East Carolina University, Greenville, North Carolina, USA

<sup>2</sup>Department of Pediatrics, Brody School of Medicine at East Carolina University, Greenville, North Carolina, USA

<sup>3</sup>ECU Health Medical Center, Greenville, North Carolina, USA

#### Correspondence

Dmitry Tumin, Department of Pediatrics, Brody School of Medicine at East Carolina University, 600 Moye Blvd, Greenville, NC 27834 USA Email: tumind18@ecu.edu

Funding information None.

#### Abstract

Objective: Adolescence is a critical period of transition from paediatric to adult health care, but readiness for this transition has been described as low in the general adolescent population. We aimed to investigate whether transition readiness improved over time among US adolescents and to examine associations between demographic and clinical characteristics and transition readiness over time.

Methods: Deidentified caregiver-reported repeated cross-sectional data from the 2016-2020 National Survey of Children's Health were analysed for caregiverreported measures of transition readiness among adolescents age 12-17 years. Logistic regression was used to identify trends in transition readiness and change over time in factors associated with this outcome.

**Results:** Among 55 022 adolescents represented in the five survey years, the proportion meeting a composite definition of transition readiness increased from 15% (95% confidence interval [CI]: 14%, 16%) in 2016 to 19% (95% CI: 17%, 20%) in 2020. After multivariable adjustment, each additional year was associated with 12% greater odds of caregiver-reported transition readiness (95% CI: +8%, +15%; P < 0.001), and transition readiness was more likely for girls, older adolescents and adolescents with special health care needs. Associations between adolescent characteristics and transition readiness did not change over the study period.

Conclusions: Population-level caregiver-reported transition readiness among US adolescents has increased but remains low. Factors previously associated with transition readiness (age, sex, race and ethnicity, family income and presence of special health care needs) have persisted over recent years.

KEYWORDS adolescence, transition

#### INTRODUCTION 1 |

Adolescence is a critical period of transition, which includes assuming responsibility for one's health and well-being. (Lebrun-Harris

et al., 2018; Monaghan et al., 2013; White et al., 2018; Wiener et al., 2007) Transition readiness, or the individual's readiness to manage their health care needs and shift from paediatric to adult health care providers, is crucial during this time.

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made. © 2022 The Authors. Child: Care, Health and Development published by John Wiley & Sons Ltd.

(Eaton et al., 2017) The components of an effective transition include (a) self-determination, (b) accountability, (c) acknowledgement of individual differences and complexities, (d) recognition of vulnerabilities and the influence of culture and socioeconomic status and (e) early preparation and caregiver support for building the adolescent's knowledge of their health condition. (White et al., 2018) Barriers to an effective transition of care may include inadequate communication between the family and health care providers, limited educational attainment or health literacy, limited access to health services, language barriers and socioeconomic disadvantages, including un- or under-insurance. (McKenzie et al., 2019; Naylor & Keating, 2008)

Programmes to improve transition readiness have included a transition navigator, mobile applications to follow the plan of care and beginning the transition process several years before the transition occurs. (Child and Adolescent Health Measurement Initiative, 2017; Manwani et al., 2021; McKenzie et al., 2019) Various measures have been proposed to evaluate the impact of such programmes, as well as levels of transition preparation and transition success. For example, psychometrically validated questionnaire-based measures have included the Transition Readiness Assessment Questionnaire (TRAQ) and Self-Management and Transition to Adulthood with Treatment (STARx) questionnaire, completed by adolescents; and the STARx-Parent questionnaire (STARx-P), completed by caregivers. (Ferris et al., 2015; Nazareth et al., 2018; Wood et al., 2014) However, no standardized guestionnaire-based definition exists, and guestionnairebased definitions have generally not been validated in comparison to future patterns of health care use. (Okumura et al., 2022; Straus, 2019) Furthermore, even when data on health care utilization in young adulthood can be analysed, there is no standardized measure of successful transition based on health care utilization. (Fair et al., 2016)

Despite controversy over the measurement of transition readiness, tracking trends in transition readiness represents an urgent need. In the United States, recent studies have documented low levels of transition readiness, (Lebrun-Harris et al., 2018) with an analysis of the 2009-2010 National Survey of Children's Health (NSCH) finding that only 32% of youth with special health care needs (SHCNs) received adequate transition preparation. (McKenzie et al., 2019) More recent national surveys have described that between 17% and 40% of adolescents are ready for transition to adult care, (Lebrun-Harris et al., 2018; Zablotsky et al., 2020) whereas individual centers have reported much greater success in preparing adolescents for transition. (Calhoun et al., 2019; Sawicki et al., 2014) Using repeated cross-sectional data from the 2016-2020 NSCH, we aimed to determine whether a composite measure of caregiver-reported transition readiness has improved among US adolescents in recent years. Our secondary aims were to explore which components of transition readiness accounted for any trend in the composite outcome and whether factors associated with transition readiness have changed over this period.

## 2 | METHODS

This study analysed data from 2016 to 2020 NSCH, a nationally representative annual survey of households with children ages 0-17 years. The survey is conducted by the US Census Bureau, focusing on children's health and access to care, and designed to collect data for reporting nationwide and state-level health care quality measures defined by the Maternal and Child Health Bureau (MCHB; including a composite measure of transition readiness). (Health Resources and Services Administration (HRSA); Maternal and Child Health, n.d.; Ghandour et al., 2018) Beginning in 2016, the NSCH used a selfadministered web or paper questionnaire completed by a knowledgeable caregiver about one randomly selected child in each household. (Ghandour et al., 2018) Questionnaire design was guided by a technical expert panel of national leaders in child health, who collaborated with MCHB staff to update and refine questions on health care transition that had been used in older iterations of the NSCH. (Ghandour et al., 2018) For our study, we included data on adolescent ages 12-17 years. We excluded cases with missing data on transition readiness questions due to item non-response, as well as cases with missing data on other study variables.

Over the 5 years included in our study, transition readiness was measured using four questions completed by caregivers. (Child and Adolescent Health Measurement Initiative, 2016) Among adolescents currently seeing a paediatric health care provider, the survey asked if this provider talked with the caregiver about having the adolescent eventually see health care providers who treat adults. This question was recoded as 'yes' if the adolescent was no longer seeing paediatric health care providers. The second question was whether the adolescent's health care provider actively worked with the adolescent to help them gain skills to manage his or her health. The third question was whether the adolescent's health care provider actively worked with the adolescent to help them understand the changes in health care that happened at age 18. The fourth question was whether the adolescent had a chance to speak with a health care provider privately at their last preventive checkup. This question was recoded as 'no' if the adolescent did not complete a preventive checkup in the past 12 months. Our primary analysis focused on a composite measure of transition readiness, defined as answering 'yes' to all 4 questions. This definition was aligned to the 'Transition to Adulthood' National Performance Measure defined by MCHB, and our coding was based on the technical definition of this measure provided by MCHB. (HRSA, n.d.; Georgetown University National Center for Education in Maternal and Child Health, 2014)

Covariates that may have influenced transition planning and readiness included the sex of the adolescent, the adolescent's race and ethnicity (Hispanic, non-Hispanic White, non-Hispanic Black, other), the adolescent's age in years, caregivers' highest educational attainment level (less than high school, high school or equivalent, some college or bachelor's degree), household income as a proportion of the Federal poverty level (<100%, 100–199%, 200–399% or ≥400%) and the adolescent's health insurance coverage type (private coverage only, any public coverage or no coverage). (Miller et al., 2019) Adolescent health status was determined using a caregiver-rated 5-point scale of general health (from poor to excellent), and a measure of SHCN described in detail elsewhere, which addressed presence of chronic health conditions resulting in functional limitation or requiring medications or health services in excess of those typically needed by the adolescent's peers. (Miller et al., 2019; Ross et al., 2021)

Survey weights were applied to all analyses to account for unequal probability of participation in the NSCH, and variance estimates were adjusted for the complex survey design. Multiply imputed income data were used for households missing data on the poverty measure, with model estimates combined across imputed data sets as recommended by the survey technical documentation. (US Census Bureau, n.d.) Data were summarized using weighted means or proportions with 95% confidence intervals (CIs). We compared adolescent characteristics according to the overall measure of transition readiness using Wald tests, except for poverty categories, which were compared using unadjusted logistic regression due to the inclusion of multiply imputed data. Unadjusted and adjusted logistic regression was used to check for trends in the overall transition readiness measure between the years 2016 and 2020. For our secondary aim, we refit the multivariable model for each of the component questions of the transition readiness measure. In the secondary analysis of the composite measure, we sequentially tested interactions between survey year and each covariate and included all statistically significant interactions in a final multivariable model. Data analysis was completed using Stata/IC 16, and P < 0.05 was considered statistically significant.

**TABLE 1** Weighted proportions or means with 95% confidence intervals for study variables, according to readiness for transition to adult health care ( $N = 55\ 022$ )

Variable	Adolescents not meeting transition readiness criteria ( $N = 43731$ )	Adolescents meeting transition readiness criteria ( $N = 11 291$ )	Р
Sex			
Male	0.52 (0.51, 0.53)	0.48 (0.46, 0.50)	0.001
Female	0.48 (0.47, 0.49)	0.52 (0.50, 0.54)	0.001
Race/ethnicity			
Non-Hispanic White	0.53 (0.52, 0.54)	0.57 (0.55, 0.59)	0.007
Non-Hispanic Black	0.14 (0.13, 0.15)	0.14 (0.12, 0.15)	0.650
Hispanic or Latino	0.23 (0.22, 0.25)	0.21 (0.19, 0.24)	0.233
Other	0.09 (0.09, 0.10)	0.09 (0.08, 0.10)	0.085
Age (years)	14.3 (14.2, 14.3)	15.2 (15.1, 15.2)	<0.001
Caregiver educational attainment			
Less than high school	0.09 (0.08, 0.10)	0.09 (0.08, 0.12)	0.406
High school or equivalent	0.18 (0.17, 0.19)	0.18 (0.16, 0.20)	0.930
Some college	0.22 (0.21, 0.22)	0.22 (0.21, 0.24)	0.473
Bachelor's degree	0.52 (0.51, 0.53)	0.50 (0.48, 0.52)	0.213
Family income (%FPL)			
<100%	0.16 (0.15, 0.17)	0.18 (0.15, 0.20)	0.080
100-199%	0.21 (0.19, 0.22)	0.20 (0.18, 0.22)	0.743
200-399%	0.28 (0.27, 0.29)	0.27 (0.25, 0.29)	0.223
≥400%	0.35 (0.34, 0.36)	0.35 (0.33, 0.37)	0.692
Insurance coverage type			
Private coverage only	0.63 (0.62, 0.64)	0.63 (0.60, 0.65)	0.731
Any public coverage	0.32 (0.31, 0.33)	0.33 (0.30, 0.35)	0.480
No coverage	0.05 (0.05, 0.06)	0.05 (0.04, 0.06)	0.412
Caregiver-rated health			
Poor	0.004 (0.003, 0.01)	0.003 (0.001, 0.01)	0.678
Fair	0.02 (0.02, 0.02)	0.02 (0.01, 0.02)	0.657
Good	0.11 (0.10, 0.11)	0.12 (0.10, 0.14)	0.184
Very good	0.28 (0.27, 0.29)	0.27 (0.25, 0.28)	0.272
Excellent	0.59 (0.58, 0.60)	0.59 (0.57, 0.62)	0.906
SHCN status	0.28 (0.27, 0.29)	0.32 (0.30, 0.34)	0.003

Abbreviations: FPL, federal poverty level; SHCN, special health care needs.

## 3 | RESULTS

The 2016–2020 NSCH included data on 71 973 adolescents ages 12–17. We excluded 15 875 cases with missing data on one or more of the transition questions and 1076 cases with missing data on other study variables. Based on the final sample of 55 022 adolescents, 18% (95% CI: 17%, 18%) met the composite definition of transition readiness across all 5 years. This percentage increased from 15% (95% CI: 14%, 16%) in the 2016 survey to 19% (95% CI: 17%, 20%) in the 2020 survey, although the highest proportion was attained in 2019 (20%; 95% CI: 19%, 22%). Table 1 summarizes adolescent

**TABLE 2** Multivariable logistic regression of readiness for transition to adult health care (N = 55022)

Variable	OR	95% CI	Р
Survey year <sup>a</sup>	1.12	1.08, 1.15	<0.001
Sex			
Male	Ref.		
Female	1.18	1.07, 1.30	0.001
Race/ethnicity			
Non-Hispanic White	Ref.		
Non-Hispanic Black	0.84	0.72, 0.98	0.030
Hispanic or Latino	0.80	0.68, 0.96	0.013
Other	0.86	0.75, 0.99	0.037
Age (years)	1.37	1.33, 1.42	<0.001
Caregiver educational attainment	t		
Less than high school	Ref.		
High school or equivalent	0.88	0.65, 1.17	0.376
Some college	0.89	0.68, 1.18	0.434
Bachelor's degree	0.86	0.64, 1.16	0.329
Family income (%FPL)			
<100%	Ref.		
100-199%	0.85	0.69, 1.06	0.152
200-399%	0.79	0.64, 0.98	0.031
≥400%	0.80	0.64, 0.98	0.036
Insurance coverage type			
Private coverage only	Ref.		
Any public coverage	1.01	0.87, 1.18	0.824
No coverage	0.87	0.68, 1.11	0.262
Caregiver-rated health			
Poor	Ref.		
Fair	1.25	0.46, 3.39	0.654
Good	1.80	0.71, 4.56	0.214
Very good	1.64	0.66, 4.11	0.290
Excellent	1.87	0.75, 4.67	0.182
SHCN status	1.18	1.06, 1.32	0.002

Abbreviations: CI, confidence interval; FPL, federal poverty level; OR, odds ratio; Ref., reference; SHCN, special health care needs.

<sup>a</sup>OR represents the change in the odds of transition readiness for each subsequent survey year.

characteristics in the overall sample according to whether they met or did not meet criteria for transition readiness. Adolescents deemed by their caregivers to be ready for transition to adult care were older, more likely to be female, more likely to be non-Hispanic White and more likely to have SHCN, compared with adolescents not meeting the composite measure of transition readiness.

On univariate analysis, each subsequent calendar year was associated with 10% greater odds of transition readiness (odds ratio [OR]: 1.10; 95% CI: 1.07, 1.14, P < 0.001). After adjustment for adolescent characteristics (Table 2), we confirmed a trend of increasing transition readiness over the duration of the study period (OR per year: 1.12; 95% CI: 1.08, 1.15; P < 0.001). Individual characteristics associated with greater transition readiness (according to caregiver report) included female sex, older age and presence of SHCN. Controlling for other measures of socio-economic status, adolescents in the two highest income groups were somewhat less likely to achieve the transition readiness criteria than adolescents in the lowest family income group. Additionally, in this multivariable analysis, odds of caregiverreported transition readiness were lower for Black and Hispanic adolescents, as compared with non-Hispanic White adolescents.

We repeated the multivariable model for each subcomponent of the caregiver-reported transition readiness measure, as summarized in Table 3 (detailed model results shown in Tables A1-A4). Each component was more likely to be reported by caregivers in more recent years (OR for each additional survey year ranging from 1.04-1.11; all  $P \le 0.002$ ). Female sex was associated with increased development of health management skills, whereas older age was associated with increased likelihood of reporting each of the 4 components. SHCN status was associated with increased development of health management skills, understanding the changes in health care that happen at age 18 and having the opportunity to speak privately to a health care provider at their last checkup, but decreased readiness to see health care providers who treat adults. Black and Hispanic adolescents were less likely to have discussed seeing health care providers who treat adults but more likely to have discussed the changes in health care that happen at age 18, as compared with non-Hispanic White adolescents. Lower caregiver education and lack of health insurance coverage were associated with higher likelihood of planning to see health care providers who treat adults but lower likelihood of having spoken privately to a health care provider at the last preventive visit.

In further analysis, we fit a series of unadjusted models interacting the trend in the composite measure over survey years with each individual characteristic. Among all individual characteristics, only race/ethnicity demonstrated a statistically significant interaction with survey year. After adding interactions between survey year and race/ ethnicity to the multivariable model (Table A5), we found that the only group having a statistically significant interaction with survey year was the 'other' group (not Hispanic, White or Black), as compared with non-Hispanic White adolescents. The interaction OR of 0.89 (95% Cl: 0.82, 0.98; P = 0.013) indicated that in the 'other' group, change in transition readiness for each additional survey year was attenuated by 11%. Because the adjusted trend was estimated to be an increase of 12% per year in the odds of transition readiness **TABLE 3**Multivariable logisticregressions of subcomponent measuresof readiness for transition to adult healthcare ( $N = 55\ 022$ )

Transition readiness component	OR of survey year <sup>a</sup>	95% CI	Р
Discussed seeing health care providers who treat adults	1.04	1.01, 1.07	0.002
Worked with health care providers to gain health management skills	1.11	1.08, 1.14	<0.001
Spoke with health care provider to understand changes in health care at age 18	1.09	1.06, 1.13	<0.001
Spoke with health care provider privately at last checkup	1.06	1.03, 1.09	<0.001

Abbreviations: CI, confidence interval; OR, odds ratio; SHCN, special health care needs.

<sup>a</sup>OR represents the change in the odds of transition readiness for each subsequent survey year. Each OR is from a separate model, adjusted for adolescent sex, race/ethnicity, age, insurance coverage, caregiverrated health and SHCN status, as well as for caregiver educational attainment and family income.

(Table 2), this suggested that improvements in transition readiness were not achieved among adolescents who were not Hispanic, White or Black.

#### 4 | DISCUSSION

We used repeated cross-sectional data from a nationally representative survey to track adolescents' readiness for transition to adult health care (as reported by their caregivers) over a 5-year period. Over this period, the proportion of adolescents meeting criteria for transition readiness increased from 15% to 19%. This trend encompassed all four components used to define transition readiness in our study, and based on our analyses, the social and clinical determinants of transition readiness that were examined in this study remained unchanged from 2016 to 2020. Despite the positive trend in transition readiness, the proportion of adolescents meeting criteria for transition readiness falls well short of goal levels (Georgetown University National Center for Education in Maternal and Child Health, 2014) and is much lower in these nationally representative data than in single-centre studies describing successful transition initiatives. (Calhoun et al., 2019; Sawicki et al., 2014) Although we cannot determine the specific cause of the positive trend in transition readiness in the NSCH data, we speculate that with transition preparation gaining attention across the country (and internationally), many similar local programmes are being implemented to improve transition, which are not described in the literature or captured in national or multicentre databases. Therefore, further work should prioritize scaling up transition programmes to cover a broader range of care settings and reach a greater number of adolescents, while also systematically evaluating the impact of local transition preparation programmes on populationbased transition readiness outcomes.

Consistent with prior studies, we found that females, older adolescents, non-Hispanic White adolescents and adolescents with SHCN were noted to have a higher likelihood of meeting the composite measure for transition readiness. (Lebrun-Harris et al., 2018; McKenzie et al., 2019; Zablotsky et al., 2020) Higher transition readiness among adolescents with SHCN could be explained by more frequent encounters with health care providers and thus more opportunities for discussion and preparation for the health care transition process. Patients with SHCN also often require greater care coordination due to the complexity of their conditions and often see one or more subspecialists who may facilitate transition of care. (Lebrun-Harris et al., 2018; McKenzie et al., 2019; Morton et al., 2021) Conversely, healthier adolescents who may have minimal or very few encounters with health care providers might have fewer opportunities to discuss and prepare for transition, representing a population who is vulnerable to being unprepared for transition of care.

In our multivariable analysis of the composite transition readiness measure, we found that non-Hispanic White adolescents were most likely to be ready for transition according to caregiver report. This finding differs from an earlier analysis of the 2016 NSCH data, which identified no differences in transition readiness by race and ethnicity after multivariable adjustment. (Lebrun-Harris et al., 2018) However, studies using other measurements of transition readiness have similarly reported that non-Hispanic White adolescents had higher readiness for transition to adult care. (Javalkar et al., 2016) These findings may be related to provider bias in communicating with adolescent patients and their families. (Johnson, 2020) Additionally, racial and ethnic differences in transition readiness may be influenced by ecological (e.g., neighbourhood) characteristics, racial and ethnic differences in the prevalence of specific chronic conditions, access to health care and social determinants of health not captured in our study. (Haarbauer-Krupa et al., 2019; Javalkar et al., 2016) Notably, our secondary analyses replicated the earlier finding of Lebrun-Harris et al. (Lebrun-Harris et al., 2018) insofar as race and ethnicity had different associations with different components of transition readiness. Therefore, future research should consider detailed measures of transition readiness to ensure that transition preparation is provided equitably to all adolescents.

Various questionnaire-based definitions for transition readiness have been proposed in the literature, with several tools such as the TRANSITION-Q, STARx and TRAQ undergoing formal psychometric validation. (Ferris et al., 2015; Klassen et al., 2015; Nazareth et al., 2018; Okumura et al., 2022; Straus, 2019; Wood et al., 2014) However, deployment of these validated questionnaires has been et al., 2016)

primarily carried out within the context of specific research studies or quality improvement initiatives aimed at improving the success of health care transition. By contrast, validated questions on transition readiness have not been incorporated into larger national surveys tracking population health among adolescents. Although the NSCH questions on transition readiness have not been validated in the same manner as other questionnaires described in the literature. data on transition readiness from this survey have two important advantages: First, these data are aligned with national quality metrics for assessing transition readiness (Georgetown University National Center for Education in Maternal and Child Health, 2014); and second, these data are available from a multi-year, nationally representative sample. Nevertheless, we acknowledge that the elements assessed by the NSCH measure are not sufficient to completely measure adolescents' preparation for transition to adult care and that ultimate outcomes of receiving health care from providers who treat adults are unknown. In the United States, availability of nationally representative, all-payor, population-based data on health care utilization is limited, and so population surveys are likely to remain the mainstay of assessing national trends in health care transition. Therefore, an important direction for further research is to validate the questionnaire-based measures of transition readiness with respect to subsequent health care use

once the subjects of these surveys reach adulthood.

Our results emphasize the need for more robust support for patient transition from paediatric to adult health care. Successful transition programmes have emphasized patient education, patientprovider communication, formation of joint adult/paediatric clinics and appointment of transition coordinators. (Cole et al., 2015; Crowley et al., 2011; Nurre et al., 2019) Yet, acceptability and sustainability appear to be major limitations to current implementation of organized transition protocols. Lack of psychosocial support, issues with billing and high no-show rates have also been cited as significant barriers to implementation of successful transition processes. (Nurre et al., 2019) For adolescents and young adults with chronic illnesses, dedicated transition clinics can improve clinic visit adherence and disease control, while reducing hospital admissions and Emergency Department visits. (Blinder et al., 2013; Cole et al., 2015; Crowley et al., 2011; Manwani et al., 2021; Monaghan et al., 2013; Nurre et al., 2019; Tassiopoulos et al., 2020) It remains to be seen whether these services could be replicated at other centers or health systems and whether similar improvements in providing high-value, costeffective care can be realized with the general adolescent and young adult population.

Our conclusions are constrained by several limitations of the data. First, measures of transition readiness were based on caregiver perception and did not include provider or patient perspectives. Second, data were collected using a self-administered survey, leading to potential differences among respondents in interpretation of questions, and potential recall bias. Third, consistent data were available only over a 5-year period, limiting analysis of long-term

trends. Additionally, the COVID-19 pandemic may have affected responses on the 2020 survey, which was conducted after pandemic-related lockdowns began in the United States in March 2020. However, the peak prevalence of transition readiness achieved in the 2019 survey (20%) was not substantially higher than the prevalence of caregiver-reported transition readiness in 2020 (19%). In the NSCH, available data on adolescents and their families predominantly describe non-modifiable demographic and clinical characteristics, such as race and ethnicity or presence of SHCNs. Collection of additional data on modifiable factors such as selfmanagement skills could strengthen implications for clinical practice aimed at improving transition readiness. Lastly, detailed data on health care use were unavailable in the survey, such that we could not ascertain where adolescents received information on transition to adult care or how improved transition readiness was associated with subsequent use of health care resources.

## 5 | CONCLUSION

(Fair

Structured and purposeful health care transitions from paediatric to adult health care can be associated with improved health outcomes and reduced use of acute care. (Blinder et al., 2013; Cole et al., 2015; Tassiopoulos et al., 2020) At the population level, however, adolescents' readiness for transition to adult care remains low, despite a steady trend of increasing transition readiness according to caregiver report from 2016 to 2020. Reasons for this increase are not directly evident from the NSCH data, and more robust collection of data on transition preparation is needed, to correlate effects of transition programmes implemented within single health systems with positive trends in transition readiness in multi-centre or national samples. Another important future direction for research is to more thoroughly validate the measures used to track transition readiness among the adolescent population and to demonstrate that guestionnaire-based measures of transition readiness agree with measures of health care utilization obtained after an adolescent has reached adulthood. Lastly, our data indicate that social and clinical determinants of transition readiness appear to have been stable over 2016-2020, suggesting a need to consider how demographic disparities in transition readiness could be overcome in the future.

#### CONFLICT OF INTEREST

None declared for all authors.

#### ETHICS STATEMENT

This study did not include human subject research.

#### AUTHOR CONTRIBUTIONS

MM performed the study design, data collection, data analysis and drafting of the manuscript; ABB performed the study design, interpretation of results and drafting of the manuscript; DT performed the study design, interpretation of results and critical revision of the manuscript.

#### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

#### ORCID

Dmitry Tumin ( https://orcid.org/0000-0002-9180-7656

#### REFERENCES

- Blinder, M. A., Vekeman, F., Sasane, M., Trahey, A., Paley, C., & Duh, M. S. (2013). Age-related treatment patterns in sickle cell disease patients and the associated sickle cell complications and healthcare costs. *Pediatric Blood & Cancer*, *60*(5), 828–835. https://doi.org/10.1002/pbc. 24459
- Calhoun, C. L., Abel, R. A., Pham, H. A., Thompson, S., & King, A. A. (2019). Implementation of an educational intervention to optimize selfmanagement and transition readiness in young adults with sickle cell disease. *Pediatric Blood & Cancer*, 66(7), e27722. https://doi.org/10. 1002/pbc.27722
- Child and Adolescent Health Measurement Initiative. (2016). National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [11/20/2020] from [www. childhealthdata.org].
- Child and Adolescent Health Measurement Initiative. (2017). National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [11/20/2020] from [www. childhealthdata.org].
- Cole, R., Ashok, D., Razack, A., Azaz, A., & Sebastian, S. (2015). Evaluation of outcomes in adolescent inflammatory bowel disease patients following transfer from pediatric to adult health care services: Case for transition. *The Journal of Adolescent Health*, 57(2), 212–217. https:// doi.org/10.1016/j.jadohealth.2015.04.012
- Crowley, R., Wolfe, I., Lock, K., & McKee, M. (2011). Improving the transition between paediatric and adult healthcare: A systematic review. *Archives of Disease in Childhood*, 96(6), 548–553. https://doi.org/10. 1136/adc.2010.202473
- Eaton, C. K., Davis, M. F., Gutierrez-Colina, A. M., LaMotte, J., Blount, R. L., & Suveg, C. (2017). Different demands, same goal: Promoting transition readiness in adolescents and young adults with and without medical conditions. *Journal of Adolescent Health*, 60, 727–733. https://doi.org/10.1016/j.jadohealth.2017.01.002
- Fair, C., Cuttance, J., Sharma, N., Maslow, G., Wiener, L., Betz, C., Porter, J., McLaughlin, S., Gilleland-Marchak, J., Renwick, A., Naranjo, D., Jan, S., Javalkar, K., Ferris, M., & International and Interdisciplinary Health Care Transition Research Consortium. (2016). International and Interdisciplinary Identification of Health Care Transition Outcomes. JAMA Pediatrics, 170(3), 205–211. https://doi.org/10. 1001/jamapediatrics.2015.3168
- Ferris, M., Cohen, S., Haberman, C., Javalkar, K., Massengill, S., Mahan, J. D., Kim, S., Bickford, K., Cantu, G., Medeiros, M., Phillips, A., Ferris, M. T., & Hooper, S. R. (2015). Self-management and transition readiness assessment: Development, reliability, and factor structure of the STARx questionnaire. *Journal of Pediatric Nursing*, 30(5), 691–699. https://doi.org/10.1016/j.pedn.2015.05.009
- Georgetown University National Center for Education in Maternal and Child Health. Transition to Adulthood. 2014. Available at: https:// www.ncemch.org/evidence/NPM-12-transition.php Accessed 13 January 2022.

- Ghandour, R. M., Jones, J. R., Lebrun-Harris, L. A., Minnaert, J., Blumberg, S. J., Fields, J., Bethell, C., & Kogan, M. D. (2018). The design and implementation of the 2016 national survey of children's health. *Maternal and Child Health Journal*, 22, 1093–1102. https://doi. org/10.1007/s10995-018-2526-x
- Haarbauer-Krupa, J., Alexander, N. M., Mee, L., Johnson, A., Wise, J., Arora Gupta, N., Schechter, M. S., Wasilewski-Masker, K., & Gilleland Marchak, J. (2019). Readiness for transition and health-care satisfaction in adolescents with complex medical conditions. *Child: Care, Health and Development*, 45(3), 463–471. https://doi.org/10.1111/ cch.12656
- Health Resources and Services Administration (HRSA); Maternal and Child Health. National Survey of Children's Health. https://mchb.hrsa.gov/ data-research/national-survey-childrens-health Accessed January 13, 2022.
- HRSA. (n.d.) National Performance Measures. Available at: https://mchb. tvisdata.hrsa.gov/PrioritiesAndMeasures/

NationalPerformanceMeasures Accessed 13 January 2022.

- Javalkar, K., Johnson, M., Kshirsagar, A. V., Ocegueda, S., Detwiler, R. K., & Ferris, M. (2016). Ecological factors predict transition readiness/selfmanagement in youth with chronic conditions. *The Journal of Adolescent Health*, 58(1), 40–46. https://doi.org/10.1016/j.jadohealth.2015. 09.013
- Johnson, T. J. (2020). Racial bias and its impact on children and adolescents. Pediatric Clinics of North America, 67(2), 425–436. https://doi. org/10.1016/j.pcl.2019.12.011
- Klassen, A. F., Grant, C., Barr, R., Brill, H., Kraus de Camargo, O., Ronen, G. M., Samaan, M. C., Mondal, T., Cano, S. J., Schlatman, A., Tsangaris, E., Athale, U., Wickert, N., & Gorter, J. W. (2015). Development and validation of a generic scale for use in transition programmes to measure self-management skills in adolescents with chronic health conditions: The TRANSITION-Q. *Child: Care, Health and Development*, 41(4), 547–558. https://doi.org/10.1111/cch.12207
- Lebrun-Harris, L. A., McManus, M. A., Ilango, S. M., Cyr, M., McLellan, S. B., Mann, M. Y., & White, P. H. (2018). Transition planning among US youth with and without special health care needs. *Pediatrics*, 142, e20180194. https://doi.org/10.1542/peds. 2018-0194
- Manwani, D., Doyle, M., Davidson, L., Mallea, M., Silver, E. J., Jackson, J., Chhabra, R., Morrone, K., Minniti, C., Rastogi, D., Stein, R. E., Oyeku, S., & Bauman, L. J. (2021). Transition navigator intervention improves transition readiness to adult care for youth with sickle cell disease. *Academic Pediatrics*, 22(21), 421–426.
- McKenzie, R. B., Sanders, L., Bhattacharya, J., & Bundorf, M. K. (2019). Health care system factors associated with transition preparation in youth with special health care needs. *Population Health Management*, 22, 63–73. https://doi.org/10.1089/pop.2018.0027
- Miller, R., Tumin, D., Hayes, D. Jr., Uffman, J. C., Raman, V. T., & Tobias, J. D. (2019). Unmet need for care coordination among children with special health care needs. *Population Health Management*, 22, 255–261. https://doi.org/10.1089/pop.2018.0094
- Monaghan, M., Hilliard, M., Sweenie, R., & Riekert, K. (2013). Transition readiness in adolescents and emerging adults with diabetes: The role of patient-provider communication. *Current Diabetes Reports*, 13, 900– 908. https://doi.org/10.1007/s11892-013-0420-x
- Morton, B., Damato, E. G., Ciccarelli, M. R., & Currie, J. (2021). Care coordination for children with special healthcare needs anticipating transition: A program evaluation. *Journal of Pediatric Nursing*, 61, 7–14. https://doi.org/10.1016/j.pedn.2021.02.024
- Naylor, M., & Keating, S. A. (2008). Transitional care. The American Journal of Nursing, 108, 58–63. https://doi.org/10.1097/01.NAJ.00003364 20.34946.3a
- Nazareth, M., Hart, L., Ferris, M., Rak, E., Hooper, S., & van Tilburg, M. A. L. (2018). A parental report of youth transition readiness: The parent STARx questionnaire (STARx-P) and re-evaluation of the STARx child

## 328 ↓ WILEY-

report. Journal of Pediatric Nursing, 38, 122–126. https://doi.org/10. 1016/j.pedn.2017.08.033

- Nurre, E., Smith, A. W., Jenkins, A., Horewitz, D., & Modi, A. C. (2019). Barriers and facilitators to developing transition clinics for adolescents and young adults with chronic conditions. *Clinical Pediatrics* (*Phila*), 58(13), 1444–1448. https://doi.org/10.1177/000992281 9875533
- Okumura, M. J., Kuo, D. Z., Ware, A. N., Cyr, M. H., & White, P. H. (2022 Epub ahead of print). Improving health care transitions for children and youth with special health care needs. *Academic Pediatrics*, 22, S7–S13. https://doi.org/10.1016/j.acap.2021.03.014
- Ross, S. M., Bogart, K. R., Smit, E., Hatfield, B., Yun, J., & Logan, S. W. (2021). Physical activity, medical home, and health behavior counseling among adolescents with special health care needs: NSCH 2016-2017. *Maternal and Child Health Journal*, 25(4), 542–553. https://doi.org/10. 1007/s10995-020-03089-w
- Sawicki, G. S., Kelemen, S., & Weitzman, E. R. (2014). Ready, set, stop: Mismatch between self-care beliefs, transition readiness skills, and transition planning among adolescents, young adults, and parents. *Clinical Pediatrics* (*Phila*), 53(11), 1062–1068. https://doi.org/10.1177/ 0009922814541169
- Straus, E. J. (2019). Challenges in measuring healthcare transition readiness: Taking stock and looking forward. *Journal of Pediatric Nursing*, 46, 109–117. https://doi.org/10.1016/j.pedn.2019.03.016
- Tassiopoulos, K., Huo, Y., Patel, K., Kacanek, D., Allison, S., Siminski, S., Nichols, S. L., & Mellins, C. A. (2020). Pediatric HIV/AIDS cohort study (PHACS). Healthcare transition outcomes among young adults with perinatally acquired human immunodeficiency virus infection in the United States. *Clinical Infectious Diseases*, 71(1), 133–141. https://doi. org/10.1093/cid/ciz747
- US Census Bureau. National Survey of Children's Health: Guide to multiply imputed data analysis. Available at: https://www2.census.gov/ programs-surveys/nsch/technical-documentation/methodology/

NSCH-Analysis-with-Imputed-Data-Guide.pdf Accessed 13 January 2022.

- White, P. H., Cooley, W., Transitions Clinical Report Authoring Group, American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, Boudreau, A. D. A., Cyr, M., Davis, B. E., Dreyfus, D. E., Forlenza, E., Friedland, A., Greenlee, C., Mann, M., McManus, M., Meleis, A. I., & Pickler, L. (2018). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*, 142, e20182587. https://doi.org/10.1542/peds. 2018-2587
- Wiener, L. S., Battles, H., Ryder, C., & Zobel, M. (2007). Transition from a pediatric HIV intramural clinical research program to adolescent and adult community-based care services: Assessing transition readiness. *Social Work in Health Care*, 46, 1–19. https://doi.org/10.1300/ J010v46n01\_01
- Wood, D. L., Sawicki, G. S., Miller, M. D., Smotherman, C., Lukens-Bull, K., Livingood, W. C., Ferris, M., & Kraemer, D. F. (2014). The Transition Readiness Assessment Questionnaire (TRAQ): Its factor structure, reliability, and validity. *Academic Pediatrics*, 14(4), 415–422. https://doi. org/10.1016/j.acap.2014.03.008
- Zablotsky, B., Rast, J., Bramlett, M. D., & Shattuck, P. T. (2020). Health care transition planning among youth with asd and other mental, behavioral, and developmental disorders. *Maternal and Child Health Journal*, 24, 796–804. https://doi.org/10.1007/s10995-019-02858-6

How to cite this article: Mulkey, M., Baggett, A. B., & Tumin, D. (2023). Readiness for transition to adult health care among US adolescents, 2016–2020. *Child: Care, Health and Development*, 49(2), 321–331. <u>https://doi.org/10.1111/cch.</u> 13047

## APPENDIX A

		-	
Variable	OR	95% CI	Р
Survey year <sup>a</sup>	1.04	1.01, 1.07	0.002
Sex			
Male	Ref.		
Female	1.07	0.98, 1.15	0.116
Race/ethnicity			
Non-Hispanic White	Ref.		
Non-Hispanic Black	0.67	0.59, 0.76	<0.001
Hispanic or Latino	0.73	0.64, 0.82	<0.001
Other	0.95	0.85, 1.05	0.310
Age (years)	1.25	1.22, 1.28	<0.001
Caregiver educational attainment	:		
Less than high school	Ref.		
High school or equivalent	0.85	0.66, 1.11	0.234
Some college	0.65	0.51, 0.85	0.001
Bachelor's degree	0.51	0.39, 0.66	<0.001
Family income (%FPL)			
<100%	Ref.		
100-199%	0.91	0.75, 1.12	0.378
200-399%	0.92	0.77, 1.10	0.381
≥400%	0.79	0.67, 0.94	0.008
Insurance coverage type			
Private coverage only	Ref.		
Any public coverage	1.04	0.91, 1.17	0.586
No coverage	1.32	1.06, 1.65	0.014
Caregiver-rated health			
Poor	Ref.		
Fair	1.35	0.61, 2.98	0.453
Good	1.82	0.89, 3.73	0.099
Very good	1.82	0.90, 3.69	0.095
Excellent	1.99	0.98, 4.02	0.056
SHCN status	0.84	0.77, 0.92	<0.001

**TABLE A1** Multivariable logistic regression of discussing seeing health care providers who treat adults (N = 55~022)

Abbreviations: CI, confidence interval; FPL, federal poverty level; OR, odds ratio; Ref., reference; SHCN, special health care needs.

<sup>a</sup>OR represents the change in the odds of transition readiness for each subsequent survey year.

nearth care providers to gain ne	ann manag		- 55 022)
Variable	OR	95% CI	Р
Survey year <sup>a</sup>	1.11	1.08, 1.14	<0.001
Sex			
Male	Ref.		
Female	1.14	1.05, 1.23	0.001
Race/ethnicity			
Non-Hispanic White	Ref.		
Non-Hispanic Black	1.19	1.04, 1.36	0.013
Hispanic or Latino	0.98	0.87, 1.11	0.779
Other	1.00	0.90, 1.12	0.989
Age (years)	1.04	1.02, 1.07	<0.001
Caregiver educational attainme	nt		
Less than high school	Ref.		
High school or equivalent	0.92	0.71, 1.19	0.540
Some college	0.96	0.75, 1.23	0.770
Bachelor's degree	0.91	0.71, 1.17	0.471
Family income (%FPL)			
<100%	Ref.		
100-199%	0.89	0.76, 1.05	0.176
200-399%	0.86	0.73, 1.02	0.087
≥400%	0.88	0.74, 1.05	0.162
Insurance coverage type			
Private coverage only	Ref.		
Any public coverage	1.02	0.91, 1.16	0.699
No coverage	0.80	0.64, 0.99	0.041
Caregiver-rated health			
Poor	Ref.		
Fair	1.23	0.52, 2.89	0.639
Good	1.42	0.64, 3.16	0.388
Very good	1.25	0.57, 2.75	0.584
Excellent	1.31	0.60, 2.90	0.499
SHCN status	1.70	1.55, 1.86	<0.001

Abbreviations: CI, confidence interval; FPL, federal poverty level; OR, odds ratio; Ref., reference; SHCN, special health care needs.

 $^{\rm a}{\rm OR}$  represents the change in the odds of transition readiness for each subsequent survey year.

**TABLE A2** Multivariable logistic regression of working with health care providers to gain health management skills (N = 55 022)

TABLE A3	Multivariable logistic regression of speaking with
health care prov	vider to understand changes in health care at age 18
(N = 55 022)	

Variable	OR	95% CI	Р
Survey year <sup>a</sup>	1.09	1.06, 1.13	<0.001
Sex			
Male	Ref.		
Female	1.01	0.92, 1.10	0.889
Race/ethnicity			
Non-Hispanic White	Ref.		
Non-Hispanic Black	1.78	1.55, 2.04	<0.001
Hispanic or Latino	1.40	1.23, 1.60	<0.001
Other	1.21	1.08, 1.35	0.001
Age (years)	1.17	1.14, 1.21	<0.001
Caregiver educational attainment			
Less than high school	Ref.		
High school or equivalent	0.90	0.69, 1.16	0.414
Some college	0.96	0.74, 1.24	0.740
Bachelor's degree	0.77	0.59, 0.999	0.049
Family income (%FPL)			
<100%	Ref.		
100-199%	0.80	0.67, 0.97	0.024
200-399%	0.74	0.62, 0.89	0.001
≥400%	0.69	0.58, 0.83	<0.001
Insurance coverage type			
Private coverage only	Ref.		
Any public coverage	0.97	0.86, 1.11	0.693
No coverage	0.93	0.74, 1.17	0.535
Caregiver-rated health			
Poor	Ref.		
Fair	1.46	0.69, 3.10	0.323
Good	1.85	0.95, 3.59	0.070
Very good	1.79	0.93, 3.44	0.080
Excellent	2.21	1.15, 4.25	0.017
SHCN status	1.14	1.04, 1.25	0.007

**TABLE A4**Multivariable logistic regression of speaking with<br/>health care provider privately at last checkup ( $N = 55\ 022$ )

Variable	OR	95% CI	Р
Survey year <sup>a</sup>	1.06	1.03, 1.09	<0.001
Sex			
Male	Ref.		
Female	0.94	0.87, 1.02	0.143
Race/ethnicity			
Non-Hispanic White	Ref.		
Non-Hispanic Black	0.94	0.82, 1.08	0.393
Hispanic or Latino	0.94	0.83, 1.07	0.335
Other	0.93	0.83, 1.04	0.197
Age (years)	1.36	1.32, 1.39	<0.001
Caregiver educational attainment			
Less than high school	Ref.		
High school or equivalent	1.15	0.89, 1.47	0.288
Some college	1.30	1.02, 1.66	0.037
Bachelor's degree	1.44	1.13, 1.85	0.004
Family income (%FPL)			
<100%	Ref.		
100-199%	1.01	0.85, 1.20	0.899
200-399%	0.95	0.80, 1.12	0.524
≥400%	1.04	0.88, 1.24	0.656
Insurance coverage type			
Private coverage only	Ref.		
Any public coverage	1.00	0.88, 1.13	0.962
No coverage	0.76	0.62, 0.94	0.012
Caregiver-rated health			
Poor	Ref.		
Fair	1.66	0.77, 3.56	0.196
Good	1.72	0.85, 3.47	0.131
Very good	1.96	0.98, 3.91	0.057
Excellent	2.08	1.04, 4.15	0.038
SHCN status	1.23	1.12, 1.35	< 0.001

Abbreviations: CI, confidence interval; FPL, federal poverty level; OR, odds ratio; Ref., reference; SHCN, special health care needs.

<sup>a</sup>OR represents the change in the odds of transition readiness for each subsequent survey year.

Abbreviations: CI, confidence interval; FPL, federal poverty level; OR, odds ratio; Ref., reference; SHCN, special health care needs.

<sup>a</sup>OR represents the change in the odds of transition readiness for each subsequent survey year.

MULKEY	ΕT	AL
--------	----	----

**TABLE A5**Multivariable logisticregression of readiness for transition to<br/>adult health care, interacting survey year<br/>with adolescent race and ethnicity<br/> $(N = 55\ 022)$ 

	Main effect <sup>a</sup>			Interaction with survey year <sup>b</sup>		
Variable	OR	95% CI	Р	OR	95% CI	Р
Survey year <sup>c</sup>	1.15	1.11, 1.18	<0.001			
Sex						
Male	Ref.					
Female	1.18	1.07, 1.30	0.001			
Race/ethnicity						
Non-Hispanic White	Ref.			Ref.		
Non-Hispanic Black	0.84	0.64, 1.12	0.241	1.00	0.90, 1.11	0.965
Hispanic or Latino	0.96	0.73, 1.27	0.783	0.92	0.83, 1.03	0.140
Other	1.10	0.88, 1.37	0.408	0.89	0.82, 0.98	0.013
Age (years)	1.38	1.33, 1.42	<0.001			
Caregiver educational attainme	nt					
Less than high school	Ref.					
High school or equivalent	0.88	0.65, 1.17	0.371			
Some college	0.89	0.67, 1.18	0.421			
Bachelor's degree	0.86	0.64, 1.15	0.316			
Family income (%FPL)						
<100%	Ref.					
100-199%	0.85	0.69, 1.06	0.156			
200-399%	0.79	0.64, 0.98	0.031			
≥400%	0.80	0.64, 0.99	0.037			
Insurance coverage type						
Private coverage only	Ref.					
Any public coverage	1.02	0.87, 1.18	0.838			
No coverage	0.87	0.67, 1.11	0.256			
Caregiver-rated health						
Poor	Ref.					
Fair	1.27	0.47, 3.42	0.639			
Good	1.82	0.72, 4.60	0.203			
Very good	1.66	0.66, 4.14	0.396			
Excellent	1.89	0.76, 4.71	0.173			
SHCN status	1.18	1.06, 1.32	0.002			

Abbreviations: CI, confidence interval; FPL, Federal poverty level; OR, odds ratio; Ref., reference; SHCN, special health care needs.

<sup>a</sup>ORs represent the association between each covariate and transition readiness in the earliest survey year (2016).

<sup>b</sup>ORs represent the multiplicative modification of the survey year trend for each category listed. <sup>c</sup>OR represents the change in the odds of transition readiness for each subsequent survey year, among non-Hispanic White adolescents. The OR of survey year is modified for other race/ethnicity groups by the interaction terms in the right-hand columns.