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## Measuring health care transition: Across time and into the future

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## ABSTRACT

**Problem:** Youth with special health care needs often experience significant difficulty transitioning into adult health care services and adult life. Services supporting youths' transition from pediatric to adult health care (Health Care Transition (HCT)) have been a priority for nearly 30 years to improve this transition process. The Health Resources and Service Administration, Maternal and Child Health Bureau have measured HCT service provision since 2001 but the longitudinal use of this measure has never been examined (Blumberg, 2003; Maternal and Child Health Bureau, n.d.).

**Eligibility Criteria:** This manuscript highlights the consistent and inconsistent uses of HCT constructs in two prominent national surveys (the National Survey of Children with Special Health Care Needs (NS-CSHCN) and the National Survey of Children's Health (NSCH)) between 2001 and 2019. All studies utilizing an HCT measure within a national survey between the 18 years were included in this examination.

**Results:** Significant changes have been made to the measurement of HCT service provision resulting in inconsistencies over the last 18 years. Measurement criteria and survey questions have changed substantially from the NS-CSHCN and NSCH limiting one's ability to examine trends in HCT since 2001. Since 2016, few changes have been made, allowing for analysis of trends over time. Importantly, the NSCH includes added questions pertaining to HCT that are not included in the composite HCT outcome measure.

**Conclusion:** Future work should include a validation study of the HCT outcome in the National Survey of Children's Health and inclusion of additional HCT questions to promote continued and extensive use of a measure that more fully represents the needs of youth and their families.

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Services supporting the transition of youth from pediatric to adult health care have been a priority for nearly 30 years as a response to rising numbers of youth with special health care needs (YSHCN) entering adulthood, now estimated to be approximately one million each year (McManus et al., 2015). HCT services were first introduced as an important initiative by the Society of Adolescent Health and Medicine in 1993 (Blum, 1995; Blum et al., 1993). A widely cited definition of health care transition (HCT), refers to transition as "...the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care

systems (Blum et al., 1993)." Numerous policy recommendations by the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians (AAP/AAFP/ACP) soon followed (American Academy of Pediatrics et al., 2011; White & Cooley, 2018). Subsequently, additional HCT policy recommendations were issued by pediatric specialty and interdisciplinary professional organizations (Betz et al., 2016; Foster et al., 2017; Lestishock et al., 2020; Molner et al., 2019).

Federal initiatives have provided leadership to advance the development and implementation of HCT services for YSHCN. These initiatives have included programmatic service guidelines and performance standards for Title V Maternal and Child Health Services Block Grant Program that provide family-centered, comprehensive, coordinated services to eligible children, YSHCN, and their families (Maternal and Child Health Bureau, 2021). These standards include HCT service provision for transition-aged youth. Reporting requirements were instituted to track the progress of the Title V Program in achieving service outcomes; hence data were gathered using the National Survey of Children with Special Health Care Needs (NS-CSHCN) and the National Survey of Children's Health (NSCH) (Blumberg, 2003; Ghandour et al., 2018).

**Abbreviations:** YSHCN, youth with special health care needs; HCT, health care transition; AAP, American Academy of Pediatrics; AAFP, American Academy of Family Physicians; ACP, American College of Physicians; NS-CSHCN, National Survey of Children with Special Health Care Needs; NSCH, National Survey of Children's Health; CSHCN, children with special health care needs; HRSA, Health Resources and Service Administration; MCHB, Maternal and Child Health Bureau.

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The implementation of HCT services have been shown to improve YSHCN's continuity of care, health care knowledge, vocational markers, and quality of life (Beresford et al., 2013; Cheak-Zamora & Farmer, 2015; Le Roux et al., 2017; Shattuck et al., 2011). Unfortunately, the implementation of HCT services has significantly varied across different groups of youth and throughout health care settings (Leeb et al., 2020; White & Cooley, 2018; Zeng et al., 2021). Similarly, the delivery of HCT services is measured differently across interventional studies and national surveys. National surveys have measured HCT services for 18 years, however, the mechanism of consistency utilized in the HCT measure across time has not been examined. The lack of construct consistency has potential implications for tracking the changes in and progress of HCT service provision for youth, ages 12 to 17 enrolled in Title V Program for children with special health care needs (CSHCN). This paper will highlight consistent and inconsistent uses of HCT constructs and divergent operationalization of HCT measurements in two prominent national surveys used to affect HCT policy and system change initiatives. Specifically, this study examined and analyzed the use of HCT service measures in the NS-CSHCN and NSCH over the past 18 years and conclude with recommendations for consistent and cohesive future use.

## Review of HCT Measurement in National Surveys: 2001–2019

### Overview

#### NS-CSHCN and NSCH goal

The NS-CSHCNs primary goal was to collect national and state-level data on the prevalence of special health care needs in children under 18 years and examine the impact of these special needs (Blumberg, 2003; Maternal and Child Health Bureau, 2021). This survey was conducted three times- in 2001, 2005–2006, and 2009–2010. The NSCH expanded this goal to assess the health and wellbeing of all children under 18 years with and without special health care needs (Ghandour et al., 2018). This revised, consolidated survey is conducted annually, starting in 2016 and continuing to the present. Both surveys focused on various quality and access to care issues including medical home, health insurance, care coordination, access to needed services, and transition services. Both surveys have informed what we know about children's health and access to care at a state and national level influencing the quality of individual patient care, state and federal funding, and state-level health initiatives.

**HCT Measurement.** HCT service provision was selected as a service delivery goal and quality service indicator by the Health Resources and Service Administration (HRSA) Maternal and Child Health Bureau (MCHB) in the late 1990s (Blumberg, 2003; Strickland et al., 2011). Similarly, the Title V Program includes the provision of HCT services as a National Performance Measure, ensuring it will be included in each state's five-year action plan. To assist in the evaluation of this and other National Performance Measures, MCHB has funded and directed the NSCH and the NS-CSHCN since 2001 to collect national- and state-level data on child health and health care service delivery. A measure of the provision of HCT services was implemented in the first NS-CSHCN in 2001 and was most recently assessed in the 2019 NSCH (Blumberg, 2003; Ghandour et al., 2018).

#### Original measurement

The MCHB developed six core outcomes for the Title V Programs to be assessed in the 2001 and subsequent surveys. HCT was the sixth core outcome (Outcome 6) within the 2001 NS-CSHCN. The survey broadly defined HCT as "Youth with special health care needs will receive the services necessary to make transitions to adult life, including adult health care, work, and independence" (McPherson et al., 2004). The survey measured HCT service provisions utilizing four distinct criteria. The first three criteria, referred to as guidance

questions, focused on discussions between the youth and their health care provider related to 1) transferring to an adult provider, 2) changing health care needs, and 3) developing a plan for addressing said changing needs. The fourth criteria assessed the extent to which youth were preparing for independence by asking if the youth had access to vocational or career training (Table 1). To successfully meet the MCHB Outcome 6 within the NS-CSHCN, participants had to receive all three criteria identified in the guidance questions as well as indicate they had access to vocational or career training (McPherson et al., 2004; Strickland et al., 2011). The measure was restricted to YSHCN who were 12–17 years of age identified using a 5-item caregiver survey-based tool designed to reflect MCHB's definition of children with special needs. Caregivers or guardians are the respondents to all survey questions.

#### Changes in HCT questions and criteria

The next iteration of the NS-CSHCN was conducted in 2005–2006. While there are distinct similarities to the 2001 survey, significant changes were made to the MCHB Outcome 6 and HCT questions (Blumberg et al., 2008; US Department of Health and Human Services, 2007). The descriptions of each survey revision are detailed in Table 1. In both the 2001 and 2005–2006 surveys, four criteria were used to measure HCT, with three criteria assessing guidance, and one assessing preparation for independence (Table 1).

#### Changes in specific criteria

The general structure of Outcome 6 did not change between the 2001 and 2005–2006 surveys as both assessed transition guidance and the promotion of independence. Two major changes in the specific questions occurred in the 2005–2006 NS-SHCN that changed the scope of the HCT outcome measure. First, the guidance questions assessing the development of a plan in 2001 were changed to examine if providers discussed health insurance retention with the youth and families in the 2005–2006 survey. Second, the concept of youth preparation for independence was changed from assessing vocational and career training received by youth to a question assessing provider encouragement (Table 1). Specifically, participants were asked to rate how often the provider encouraged youth to take responsibility for their health care needs.

Revisions of the HCT questions in the 2016 NSCH survey and subsequent surveys included both structural changes and question changes that again altered the scope of the HCT outcome measures. While the 2016 survey has three guidance-related questions, similar to previous measures, participants meet the Outcome 6 criteria if they have answered positively to two of the guidance questions and the independence question. Specifically, participants had to indicate their health care provider: 1) discussed the transition to an adult provider, at least once (if youth did not already have an adult provider), 2) actively worked with youth to discuss changes in health care OR how to gain self-care skills, and 3) had time alone to speak to the youth during the last visit (Ghandour et al., 2018; US Census Bureau, 2018). These changes represent a reduction of guidance questions from three to two. It is important to note the NSCH requires *only one* positive response out of the three criteria if all other questions were missing or legitimately skipped.

Significant changes in question topics were also introduced. The health insurance question in 2005–2006 and 2009–2010 was replaced with a question about promoting self-care skill development (gain skills). Further, the independence question was again changed from providers encouraging youth independence (take on the responsibility) to youth having time alone with providers during the clinic visit. The NSCH is conducted annually and all subsequent surveys (2017–2019) have utilized the same HCT variables as the 2016 survey (U.S. Census Bureau, 2018).

**Table 1**  
Description of HCT Question across surveys and survey years.

HCT Criteria	2001 NS-CSHCN	2005–06 NS-CSHCN	2009–10 NS-CSHCN	2016 NSCH*	2017 NSCH	2018 NSCH	2019 NSCH
Ages in survey	13–17 years	12–17 years	12–17 years	12–17 years	12–17 years	12–17 years	12–17 years
% Meeting the HCT Outcome	YSHCN: 5.8%	YSHCN: 41%	YSHCN: 40%	YSHCN: 17% Non-YSHCN: 14%	2016–2017: YSHCN: 17% Non-YSHCN: 14%	–	–
<b>Guidance-related questions</b>							
Shift to adult provider:		<i>Slight Difference from previous survey</i>	<i>No Difference from previous survey</i>	<i>Slight Difference from previous survey</i>	<i>No Difference from previous survey</i>	<i>No Difference from previous survey</i>	<i>No Difference from previous survey</i>
Question 1	Original question Have (the selected child (SC))’s doctors or other health care providers discussed having SC eventually see a doctor who treats adults (C6Q0A_B)?	Do any of SC’s doctors or other health care providers treat only children (C6Q07)?	Do any of SC’s doctors or other health care providers treat only children (C6Q07)?	Do any of this child’s doctors or other health care providers treat only children (TREATCHILD)?	Do any of this child’s doctors or other health care providers treat only children?	Do any of this child’s doctors or other health care providers treat only children?	Do any of this child’s doctors or other health care providers treat only children?
Question 2	–	<i>Significant Difference</i> If answered yes on C6Q07: Have they talked with you about having SC eventually see doctors or other health care providers who treat adults (C6Q0A_B)?	<i>No Difference</i> If answered yes on C6Q07: Have they talked with you about having SC eventually see doctors or other health care providers who treat adults?	<i>No Difference</i> If yes, have they talked with you about having this child eventually see doctors or other health care providers who treat adults (TREATADULT)?	<i>No Difference</i> If yes, have they talked with you about having this child eventually see doctors or other health care providers who treat adults?	<i>Slight Difference</i> If yes, have they talked with you about when this child will need to see doctors or other health care providers who treat adults?	<i>No Difference</i> If yes, have they talked with you about when this child will need to see doctors or other health care providers who treat adults?
Question 3	–	<i>Significant Difference</i> If answered yes on C6Q07: Would a discussion about doctors who treat adults have been helpful to you (C6Q0A_C)?	<i>No Difference</i> If answered yes on C6Q07: Would a discussion about doctors who treat adults have been helpful to you?	–	–	–	–
Future health care needs:							
Question 1	Original question Have SC’s doctors or other health care providers talked with you or SC about how (his/her) health care needs might change when (he/she) becomes an adult (C6Q0A)?	<i>Slight Difference</i> Have SC’s doctors or other health care providers talked with you about (his/her) health care needs as (he/she) becomes an adult (C6Q0A)?	<i>No Difference</i> Have SC’s doctors or other health care providers talked with you about (his/her) health care needs as (he/she) becomes an adult?	<i>Significant Difference+</i> Has this child’s doctor or other health care provider actively worked with this child to understand the changes in health care that happen at age 18 (For example, by understanding changes in privacy, consent, access to information, or decision-making (CHANGEAGE)?	<i>No Difference</i> Has this child’s doctor or other health care provider actively worked with this child to understand the changes in health care that happen at age 18 (For example, by understanding changes in privacy, consent, access to information, or decision-making?	<i>No Difference</i> Has this child’s doctor or other health care provider actively worked with this child to understand the changes in health care that happen at age 18 (For example, by understanding changes in privacy, consent, access to information, or decision-making?	<i>No Difference</i> Has this child’s doctor or other health care provider actively worked with this child to understand the changes in health care that happen at age 18 (For example, by understanding changes in privacy, consent, access to information, or decision-making?
Question 2	–	<i>Significant Difference</i> Would a discussion about SC’s health care needs have been helpful (C6Q0A_D)?	<i>No Difference</i> Would a discussion about SC’s health care needs have been helpful?	–	–	–	–
Plan for addressing changing needs							
Plan for addressing changing needs	Original question Has a plan for addressing these changing needs been developed with SC’s doctor or other health care providers (C6Q0A_A)?	–	–	–	–	–	–

(continued on next page)

Table 1 (continued)

HCT criteria	2001 NS-CSHCN	2005–06 NS-CSHCN	2009–10 NS-CSHCN	2016 NSCH*	2017 NSCH	2018 NSCH	2019 NSCH
Self-care skills							
Future insurance needs: Question 1		Original question Eligibility for health insurance often changes as children reach adulthood. Has anyone discussed with you how to obtain or keep some type of health insurance coverage as SC becomes an adult (C6Q0A_E)?	No Difference Eligibility for health insurance often changes as children reach adulthood. Has anyone discussed with you how to obtain or keep some type of health insurance coverage as SC becomes an adult?	Significant Difference+ Has this child's doctor or other health care provider actively worked with this child to: Gain skills to manage his or her health and health care? (For example, by understanding current health needs, knowing what to do in a medical emergency, or taking medications he or she may need (GAINSKILLS))?	No Difference Has this child's doctor or other health care provider actively worked with this child to: Gain skills to manage his or her health and health care? (For example, by understanding current health needs, knowing what to do in a medical emergency, or taking medications he or she may need?)	No Difference Has this child's doctor or other health care provider actively worked with this child to: Gain skills to manage his or her health and health care? (For example, by understanding current health needs, knowing what to do in a medical emergency, or taking medications he or she may need?)	No Difference Has this child's doctor or other health care provider actively worked with this child to: Gain skills to manage his or her health and health care? (For example, by understanding current health needs, knowing what to do in a medical emergency, or taking medications he or she may need?)
Question 2		Would a discussion about health insurance have been helpful to you (C6Q0A_F)?	Would a discussion about health insurance have been helpful to you?				
<b>Independence-related Questions</b>							
Vocational or career training							
Encourage independence		Original question How often do SC's doctors or other health care providers encourage (him/her) to take responsibility for [his/her] health care needs, such as: taking medication, understanding diagnosis, or following medical advice (C6Q08A)?	No Difference How often do SC's doctors or other health care providers encourage (him/her) to take responsibility for [his/her] health care needs, such as: taking medication, understanding diagnosis, or following medical advice (C6Q08A)?				
Time alone with provider				Original question At his or her LAST preventive check-up, did this child have a chance to speak with a doctor or other health care provider privately without you or another adult in the room (DOCPIVATE)?	No Difference At his or her LAST preventive check-up, did this child have a chance to speak with a doctor or other health care provider privately without you or another adult in the room?	Slight Difference If yes (seen doctor in last 12 months), at his or her LAST medical care visit, did this child have a chance to speak with a doctor or other health care provider privately, without you or another caregiver in the room?	No Difference If yes (seen doctor in last 12 months), at his or her LAST medical care visit, did this child have a chance to speak with a doctor or other health care provider privately, without you or another caregiver in the room?

The underlined words/phrases represent slight changes in wording between survey years; \*Change in population from children with special health care needs only to children with and without special health care needs. †In the 2016–2019 NSCH only 2 guidance questions are required. If participants report positively to CHANGEAGE or GAINSKILLS that criteria are met.

Changes in format and sampling frame

Question sets to assess individual concepts in more detail were implemented in 2005–2006 and have continued. For instance, the question examining provider discussion about the shift to an adult provider was broken down into one question about the current type of provider used, a second question assessing if a discussion occurred for youth with pediatric providers, and a third question assessing if participants thought this specific discussion would have been helpful (Table 1).

The addition of this third question in the set exemplifies the first major formatting change within the HCT outcome. Within the 2005–2006 and 2009–2010 surveys, participants meet qualifications for each guidance question if they report they had received the discussion OR if they felt that the discussion would not have been helpful. If participants reported none of the HCT guidance discussions as helpful (i.e., the youth had no need for guidance (“no need”)) the participant would be identified as having met the three guidance questions, regardless of having had discussions about the transition process (Child and Adolescent Health Measurement Initiative, 2021; US Department of Health and Human Services, 2007). The perceived need or “no need” questions remained in the 2009–2010 survey and were removed in the 2016 and subsequent surveys.

The second major shift in formatting occurred with the redesign of the NS-CSHCN and NSCH. The 2009–2010 NS-CSHCN was the final HRSA MCHB national survey focusing on CSHCN only. Starting in 2012, HRSA MCHB funded an extensive redesign of the National Survey of Children’s Health (NSCH) and NS-CSHCN surveys (Ghandour et al., 2018). The result of the redesign process included combining the NSCH and NS-CSHCN surveys into one survey, the move to an annual single-year survey, and the development of a new sampling frame and data collection method (White & Cooley, 2018). These changes reflect the new HRSA MCHB sponsored data source, NSCH that includes all children’s health outcomes, both with and without SHCN. Data collection on the revised NSCH started in 2016. It utilized a multi-mode approach to data collection and families selected to participate were sent a letter containing a website link to complete the survey (Ghandour et al., 2018). The changes in sample frames and inclusion of youth with and without SHCN signifies a major change in the survey and improvements in measurement and group comparisons for the HCT outcome. HCT questions have been fairly consistent across the 2016–2019 NSCH (Table 1) and across-year comparisons are recommended (U.S. Census Bureau, 2019).

Additional HCT questions in the NSCH Survey

The NSCH Outcome 6 included three criteria (four questions total) in all survey years, the survey included a total of 13 questions related to HCT questions in 2016–2017 and 12 questions in 2018–2019 (Table 1). Additional HCT items were related to, making positive choices, planning for the future, health insurance continuity, and the content and delivery of a care plan. The 2018 survey revised the wording utilized on numerous questions, deleted two HCT questions, and added one question (Table 1). Based upon a review of published literature to date, the plan future and positive choice questions, used in Zablotsky et al. (2020) and Zeng et al. (2021), are the only examples of these additional transition questions being assessed in any peer-reviewed published study.

Changes in reported HCT rates across survey years

2001 NS-CSHCN survey

The scope of measure utilized in the 2001 HCT publication was limited. Three peer-reviewed studies utilizing the HCT questions from this dataset were published (Lotstein et al., 2005; McPherson et al., 2004; Scal & Ireland, 2005). McPherson et al. (2004) conducted the only study to utilize the HCT questions as prescribed within the NS-CSHCN (Outcome 6) including a vocational or career training question. Within this study, 5.8% of the CSHCN population received HCT services. Other studies using various HCT questions reported HCT service rates of 15–16% for CSHCN (Lotstein et al., 2005; Scal & Ireland, 2005).

2005–2006 NS-CSHCN survey

Based upon our review of the literature published to date, ten studies examined a version of the HCT outcome based on the 2005–06 NS-CSHCN (Table 2). Seven of these studies utilized all three guidance questions and included the question regarding preparation for independence (Cheak-Zamora et al., 2013; Kane et al., 2009; Lotstein et al., 2009; Park et al., 2011; Richmond et al., 2011; Richmond et al., 2012). These studies reported similar outcomes, with 41% of participants meeting the HCT outcome (Kane et al., 2009; Lotstein et al., 2009; Richmond et al., 2011; Richmond et al., 2012). The consistent use of the MCHB HCT Outcome 6 regarding transition was notable, the majority of the studies utilized all four questions in tangent with their unique subset of questions. (See Table 3.)

**Table 2**  
Transition-related questions in the National Survey of Children’s Health (NSCH) that are not currently in the HCT outcome measure (Outcome #6).

Survey Year	Survey Question*	Changes between survey years
2016–17 NSCH	Think about and plan for his or her future. (For example, by taking time to discuss future plans about education, work, relationships, and development of independent living skills (PLANFUTURE))?	• This question was removed from the 2018–2019 survey.
2016–19 NSCH	Make positive choices about his or her health (for example, by eating healthy, getting regular exercise, not using tobacco, alcohol, or other drugs, or delaying sexual activity (POSCHOICE))?	• No changes across survey years
2016–19 NSCH	Eligibility for health insurance often changes in young adulthood. Do you know how this child will be insured as he or she becomes an adult (HEALTHKNOW)?	• No changes across survey years
2016–19 NSCH	Follow-up question to HEALTHKNOW: If no, has anyone discussed with you how to obtain or keep some type of health insurance coverage as this child becomes an adult (KEEPINSADULT)?	• No changes across survey years
2018–19 NSCH	Did you and this child receive a summary of your child’s medical history (for example, medical conditions, allergies, medications, immunizations (MEDHISTORY))?	• Not included in the 2016–17 surveys
2016–2019 NSCH	Have this child’s doctors or other health care providers worked with you and this child to create a written plan to meet his or her health goals and needs (WRITEPLAN)?	• Slight wording changes in the 2018 survey from “create a written plan” to “create a plan of care.”
2016–2017 NSCH	Follow-up question to WRITEPLAN: If yes, does this plan identify specific health goals for this child and any health needs or problems this child may have and how to get these needs met (PLANNEEDS)?	• PLANNEEDS removed from 2018 to 2019 survey
2018–2019 NSCH	Does this plan of care address transition to doctors and other health care providers who treat adults (PLANNEEDS_R)?	• This question was not included in the 2016–17 surveys.
2016–2019 NSCH	Follow-up question to WRITEPLAN: Did you and this child receive a written copy of this plan of care (RECEIVECOPY)?	• Slight wording changes in the 2018 survey from “receive a” to “have access to
2016–2017 NSCH	Follow-up question to WRITEPLAN: Is this plan CURRENTLY up to date for this child (PLANUTD)?	• PLANUTD removed from 2018 to 2019 survey

\* Most questions were preceded by this description: Has this child’s doctor or other health care provider actively worked with this child to:

**Table 3**  
Examination of HCT Outcome in Studies using the National Survey of Children with Special Health Care Needs (NS-CSHCN) and National Survey of Children's Health (NSCH).

Study	Population and Subsample	Eligibility (age in year)	Health Care Transition (HCT) variables included	HCT outcome measure	Results- met HCT outcome	Results – Significant associations with HCT outcome
<b>NS-CSHCN 2001</b>						
McPherson et al., 2004	n = 5551	13–17	Adult Doctor discussion (CG00A.B); Health care needs change (CG00A); Develop plan for addressing needs (CG00A.A); Received vocational or career training (CG00B)*	Positive response on all 4 HCT questions. <sup>+</sup>	5.8%	–
Lotstein et al., 2005	n = 5533	13–17	Adult Doctor discussion (CG00A.B); Health care needs change (CG00A); Develop plan for addressing needs (CG00A.A);	Positive response on all 3 HCT questions.	15.3%	Age; Having Access to a medical home;
Scal & Ireland, 2005	n = 4332	14–17	Adult Doctor discussion (CG00A.B); Health care needs change (CG00A); Develop plan for addressing needs (CG00A.A);	Sum of the affirmative answers to HCT questions (0 to 3).	16.35% (score of 3)	Age and gender; Number of services needed; Quality of provider interaction;
<b>NS-CSHCN 2005–2006</b>						
Lotstein et al., 2009	n = 18,198	12–17	Adult Doctor discussion (CG007, CG00A.B, CG00A.C); Changing Health Care Needs (CG00A, CG00A.D); Health Insurance Retention (CG00A.E, CG00A.F); Encourage Responsibility (CG008)*;	Participants had to receive all 3 discussions or state they would not be helpful AND Usually or Always receive encouragement <sup>+</sup>	41%	Age; Gender; Household language spoken; Access to a medical home;
Kane et al., 2009	n = 16,876	12–17	All outcome 6 variables used*	Outcome 6 criteria used <sup>+</sup>	41%	Race/Ethnicity; Household education level; Household structure; Family FPL; State of residence;
Knapp et al., 2010	n = 36,956	12–17	All outcome 6 variables used*	Outcome 6 criteria used <sup>+</sup>	–	Gender; Race/Ethnicity; Severity of youth's condition; Household education level; Family FPL; Insurance status; Family/ provider partnership;
Scal et al., 2009	n = 18,189; n (arthritis) = 1052; n (diabetes) = 389;	12–17	All outcome 6 variables used*	No outcome measure reported;	–	–
Richmond et al., 2011	n = 14,449	12–17 (had MH/HCT responses measures)	All outcome 6 variables used*	Outcome 6 criteria used <sup>+</sup>	41.9%	Gender; Severity of youth's condition; Race/Ethnicity; Family FPL; Insurance status; Region of residence;
Park et al., 2010	n = 26,336	12–17	All outcome 6 variables used*	Outcome 6 criteria used <sup>+</sup>	–	–
Nishikawa et al., 2010	n = 18,198	12–17	Adult health care provider (CG007);	No outcome measure reported;	–	–
Duke & Scal, 2011	n = 18,198	12–17	All outcome 6 variables used*	No outcome measure reported;	–	–
Richmond et al., 2012	n = 18,198	12–17	All outcome 6 variables used*	Outcome 6 criteria used <sup>+</sup>	–	–
Cheak-Zamora et al., 2012	n = 18,198; n (ASD) = 806	12–17	All outcome 6 variables used*	Outcome 6 criteria used <sup>+</sup>	–	–
<b>NS-CSHCN 2009–2010</b>						
McManus et al., 2013	n = 17,114	12–18	All outcome 6 variables used*	Participants had to receive all 3 discussions or state they would not be helpful AND Usually or Always receive encouragement. <sup>+</sup>	40%	Gender; Race/ethnicity; Severity of youth's condition; Presence of EBD; Family FPL; Insurance status; Household language spoken; Access to a medical home;
Blackman and Conaway, 2014	n = 3974; n (CP) = 80; n (allergies) = 3894;	15–17	All outcome 6 variables used*	No outcome measure reported;	–	–
Zuckerman et al., 2014	n (without FL or ASD) = 37,826; n (ASD) = 6033	12–17	All outcome 6 variables used*	Outcome 6 criteria used <sup>+</sup>	–	–

Author(s)	n (FL) = 6505 n = 16,222	12–17	All outcome 6 variables used*	Outcome 6 criteria used <sup>+</sup>	40%	Gender: Race/ ethnicity; Severity of youth's condition; Family FPL; Household primary language;
Strickland et al., 2015						
Cheak-Zamora & Thullen, 2017	n = 14,223	12–17	All outcome 6 variables used*	Outcome 6 criteria used <sup>+</sup>	39% YSHCN; Range by condition: 19.1% youth with DD to 47.8% youth with PH; 40% YSHCN	Transition rates similar for youth with and without HP; Age; Race/ethnicity; ASD symptom severity; Family FPL; Insurance status; Family-centered care; Access to care coordination;
Downing et al., 2017	n = 14,939; n (HP) = 724	12–17	All outcome 6 variables used*	Outcome 6 criteria used <sup>+</sup>	7.4% youth with ASD;	
Walsh et al., 2017	n (ASD) = 1125;	12–17	All outcome 6 variables used*	Outcome 6 criteria used <sup>+</sup>	40% YOSHCHN; 11% of youth with DS;	
Nugent et al., 2018	n = 17,114	12–17	All outcome 6 variables used*	Outcome 6 criteria used <sup>+</sup>	32.1%	Age; Gender; Access to a medical home;
McKenzie et al., 2019	n = 17,114	12–18	All outcome 6 variables used* Did not exclude participants with "no need."	Outcome 6 criteria used <sup>+</sup>		
NSCH 2016 Lebrun-Harris et al., 2018	n = 20,708	12–17	Adult Doctor discussion (TREATCHILD, TREATADULT); Changing Health Care Needs (CHANGEAGE); Gain skills to manage health care (GAINSKILLS); Preventative visit with private time with the doctor (S4Q01, K4Q20R, DOCPRIVATE);*	Positive response on 3 elements: 1) Adult doctor discussion; 2) Private time; 3) Changing health care needs OR Gaining skills;+ No outcome measure was reported;	14% youth with no special needs; 17% YSHCN;	Age; For YSCHN: Access to care coordination; Written care plan;
Zablotsky et al., 2020	n (without conditions) = 14,800; n (ASD) = 586; n (MH, DD, or behavioral condition) = 4735;	12–17	Worked with youth to: Plan for future (PLANFUTURE); Make positive choices about health (POSCHOICE); Gain skills to manage health care (GAINSKILLS); Changing Health Care Needs (CHANGEAGE); Health Insurance Retention (HEALTHKNOW, KEEPINSADULT); Preventative visit with private time with the doctor (S4Q01, K4Q20R, DOCPRIVATE);			
Zeng et al., 2020	n (YOSHCHN) = 20,708; n (ASD) = 639;	12–17	Worked with youth to: Plan for future (PLANFUTURE); Make positive choices about health (POSCHOICE); Gain skills to manage health care (GAINSKILLS); Changing Health Care Needs (CHANGEAGE);	Sum of the affirmative answers to HCT questions (0, 1, and 2 or more).	2 or more HCT: 28.2% YOSHCHN; 18.8% youth with ASD	Positive social-emotional functioning;
<b>NSCH 2016–2017</b> Leeb et al., 2020 <sup>49</sup>	n = 29,286	12–17	All outcome 4 variables used	Outcome 6 criteria used <sup>+</sup>	15% overall 14.2% for youth with no mental, behavioral, or developmental disabilities. 15.8 youth with mental, behavioral, or developmental disabilities 13.9% youth with no special needs; 16.7% YSHCN;	Presence and type of MH, DD, or behavioral condition; access to treatment
Ilango et al., 2021	n = 29,617	12–17	All outcome 4 variables used	Outcome 6 criteria used <sup>+</sup>		

Notes: FPL, federal poverty level; MH, mental health condition; PH, physical health condition; ASD, Autism Spectrum Disorder; YOSHCHN, youth with other special health care needs; EBD, emotional, behavioral, or developmental condition; CP, cerebral palsy; FL, functional limits; YSHCN, youth with special health care needs; DD, developmental disability; HP, Heart Problems; DS, Down syndrome;

- Not reported

\* HCT variables used to meet the qualifications for Outcome 6 will be documented the first time they were used. The designation "all outcome 6 variables used" will identify that the criteria have been met in all subsequent studies within that survey year.

+ Indicate the HCT Outcome 6 measure criteria were used to define the outcome measure in this study. The specific criteria will be documented once with subsequent use indicated by "Outcome 6 criteria used".

Several of these studies utilized different populations, including narrowing the age range from 12 to 17 years to 14–17 years or assessed HCT in youth with specific conditions like Autism Spectrum Disorder (ASD), Juvenile Idiopathic Arthritis, Diabetes, and Cerebral Palsy (N. C. Cheak-Zamora et al., 2013; Park et al., 2011; N. Richmond et al., 2011). For subpopulations within the 2005–2006 survey, rates of Outcome 6 range from 21% for youth with ASD to 56.7% for youth with mental health issues.

#### 2009–2010 NS-CSHCN survey

Nine studies were published examining HCT service provision based on the 2009–2010 survey. Eight of the studies utilized the HCT measure as defined in the MCHB HCT outcome on transition (Table 2) (Blackman & Conaway, 2014; Cheak-Zamora & Thullen, 2017; Downing et al., 2017; McKenzie et al., 2019; McManus et al., 2013; Nugent et al., 2018; Strickland et al., 2015; Walsh et al., 2017; Zuckerman et al., 2014). Similar to the 2005–2006 survey, around 40% of participants met the criteria for the HCT Outcome 6 outcome. It is important to note that McKenzie et al. (2019) conducted a similar analysis but did not account for participants that reported: “no need” for a discussion as meeting the criteria and found a lower rate of HCT service provision of 32%.

Subsequently, rates in the HCT outcome measure varied greatly when analyzed by state and disability groups. Youth with ASD had the lowest rates with 7.9% meeting Outcome 6 criteria followed by youth with Down Syndrome (11%), Developmental Disabilities (19%), and physical health conditions (47.8%) (Cheak-Zamora & Thullen, 2017; Nugent et al., 2018; Walsh et al., 2017).

#### 2016 and 2017 NSCH surveys

As noted previously, significant changes were made to the 2016 NSCH survey including expanding the eligibility criteria to all youth 12–17 years of age for this measure. Similar to the changes observed between the 2001 and 2005–2006 surveys results, the rates reported on the 2009–2010 and 2016 surveys for Outcome 6 were significantly different.

Four studies have been conducted utilizing the HCT questions from the 2016 NSCH and one additional study utilized the combined 2016 and 2017 data (Table 2) (Ilango et al., 2021; Lebrun-Harris et al., 2018; Leeb et al., 2020; Zablotsky et al., 2020; Zeng et al., 2021). Three of these studies utilized the HCT measure as defined in the MCHB HCT Outcome 6. Each study found that YSHCN were more likely to receive HCT service than those without SHCN. Specifically, rates of HCT service provision varied from 17% for YSHCN and 15% for youth with a mental, behavioral or developmental disability to 14% for youth without special health care needs (Ilango et al., 2021; Lebrun-Harris et al., 2018; Leeb et al., 2020).

#### 2018 and 2019 NSCH surveys

Based upon a review of the literature published to date there has not been a published study that has assessed HCT service provision utilizing the 2018 or 2019 NSCH.

## Discussion

Examination of HCT service measures used NS-CSHCN and NSCH surveys over the past 18 years reveal the ongoing attention directed to measure, track, and assess HCT service provision as a prioritized performance standard for Title V Maternal and Child Health Services Block Grant Programs. Nevertheless, challenges to accurately track progress with this performance standard are evident as the measurement of HCT has been operationalized inconsistently in both NS-CSHCN and NSCH surveys.

Since 2001, national surveys containing items about HCT service provision have consistently focused on healthcare providers having conversations with patients about moving to an adult provider, youths' changing needs, and improving youths' independence. The

2001 survey included a broader scope of service requirements including vocational support (Blumberg, 2003). While this most closely aligns with the AAP/AAFP/ACP definition and policy recommendations around HCT service provision, the scope of the survey was narrowed to health care service provision and health-related independence in the 2005–2006 survey and has continued to have a narrower scope. Since 2005, items have focused on the HCT preparation, only one aspect of the recommended process, which include extended HCT preparation, transfer of care support, and post-transfer follow-up (American Academy of Pediatrics et al., 2002; American Academy of Pediatrics et al., 2011; Betz, 2017; US Department of Health and Human Services, 2007). More recent literature utilizes this comprehensive understanding of HCT services, based on a developmental and interagency framework, delineating the conceptual differences between the HCT preparation transfer of care, and post-transfer (Betz, 2017). It is relevant to acknowledge that the extent to which HCT services are provided is primarily relegated to the preparatory period (ages 12 to 17 years) prior to the commonly accepted period of actual transfer of care and transition into adulthood between 18 and 21 years of age. As such, the HCT measure found in the NS-CSHCN and NSCH surveys does not fully nor adequately captured this pivotal period that is determinant of the HCT services process.

The 2005–2006 and 2009–2010 national surveys incorporate caregivers' perceived need for HCT services (no need) in their definition of HCT service provision. Within the 2005–2006 surveys, participants were asked to assess if they needed each HCT service. If the participant (i.e., the youth's caregiver) indicated the service was not needed; their receipt of that service was no longer included in the criteria for meeting the HCT outcome. In the most extreme case, a participant could indicate no HCT guidance questions were needed, leaving the provider encouragement question as the sole indicator of HCT services. In contrast, the 2001 and the 2016–2019 surveys based the provision of HCT service on the actual delivery of the service, without the caregiver's assessment of need (White & Cooley, 2018). It is likely that the differences observed in rates of HCT service provision between 2001, 2005–2006, 2009–2010, and 2016 are due to the addition of the “no need” questions (i.e., the youth had no need for guidance) in 2005 and their removal in 2016. HCT service provision was highest at 40–41% in the surveys with the “no need” option and was dramatically lower in surveys without this option—5.8% in 2001 and 14–17% in 2016 and 2017. Previous studies have shown caregivers appreciation for and desire to continue pediatric relationships into adulthood, so it is likely, and not surprising, that many caregivers indicate not needing guidance for the transfer to adult providers thus increasing rates of HCT service provision within those years (Cheak-Zamora et al., 2015; N. C. Cheak-Zamora & Teti, 2015; Mazurek et al., 2021).

To date, the HCT measure was most frequently and consistently used within the 2005–2006 and 2009–2010 surveys. Twenty peer-reviewed studies have examined HCT questions or the outcome measure in the 2005–2006 and 2009–2010 surveys. Eighteen of these studies utilized the MCHB HCT outcome measure (Outcome 6). As previously aforementioned, only one study utilized the HCT outcome measure in the 2001 survey and only three studies have used the 2016 and 2017 HCT outcome measures as recommended (Lebrun-Harris et al., 2018; Leeb et al., 2020; McPherson et al., 2004).

#### Summary of achievements

The inclusion of HCT service provision measures utilized consistently over the last 18 years indicates the importance of this topic across providers, researchers, and funding sectors. The assessment of HCT service provision across time led to new initiatives such as state and regional tracking, prioritization at the state and federal level, the inclusion of transition services in health care policies like the Affordable Care Act, Employment First Initiative, and the creation of the MCHB Center for Health Care Transition Improvement (Federal Partners in

Transition Strategic Planning Committee, 2015). Utilizing the NS-CSHCN and NSCH data, researchers have identified disparities in HCT service provisions across and within special needs populations (Cheak-Zamora et al., 2013; McManus et al., 2015; White & Cooley, 2018).

The advances to date have led to many strengths regarding the inclusion of HCT service provision outcomes across the years, including the focus on services provided and independence and coordination between HCT measurement outcome and guidelines and funding requirements (American Academy of Pediatrics et al., 2011). The focus on service provision, specifically how health care providers were implementing transition discussions, was a revolutionary step as it prioritizes the various needs of youth when implemented in 2001. Providing guidance and promoting independence was an extension of the health care provider's responsibilities at the time. Adding these questions to a national survey and evaluating them in regional and state Title V funding requirements expanded the practice approaches of health care providers and helped the health care system move to a more holistic and person-centered view of health care (Maternal and Child Health Bureau, 2021).

Further, promoting independence for YSHCN was an important step in seeing people with disabilities as a whole person and able to be self-sufficient. Initially, the implementation of this concept was limited (one question in surveys between 2001 and 2010), but it set an important precedent. HCT provision questions expanded on this precedent in the 2016–2019 surveys by assessing if providers encouraged youth to gain new skills and promoted private time between youth and the provider. While these additions may seem small, once again, they expand how researchers, clinicians, and policymakers define quality care and normalize this care for all youth.

The consistent definition of HCT service provision in 2005–2010 improved our understanding of HCT services, the use of the measure, and the ability to identify trends over time. While the definition changed significantly in 2016, the NSCH utilized the same questions to assess HCT provision in 2016, 2017, 2018, and 2019 surveys, with only slight wording changes in 2018 to improve clarity. Additional in-depth documentation of the questions assessed, and measurement codes were released with the 2019 survey, making the measure easier to use and document. This change is expected to improve the utilization of the HCT measure in years to come. Lastly, the HCT outcome measure has consistently reflected guidelines introduced by leading organizations in pediatrics, family, and adult medicine; these measures reflect a medical-centric approach to care. Aligning the HCT measure with professional guidelines, designating HCT services as a National Performance Measure for the Title V Program, and consistently including the measure in NS-CSHCN and NSCH surveys have allowed for timely and reliable reporting of HCT provision across the country (Kogan et al., 2015). Future alignment with professional guidelines will include extending the age groupings of adolescents into the pivotal period of the actual transfer of care to adult services and transition into adulthood.

## Recommendations

The overall implementation of HCT measures has been an asset, but there are substantial limitations with how it has been defined, implemented, and tested. These challenges include the narrow scope of the measure across time, the limited number of variables included in the outcome measure, handling of participant preferences and missing data, and lack of validation of the outcome measure. Utilizing a service delivery outcome to assess HCT has resulted in leaving out many other aspects of the transition to adult health care services (American Academy of Pediatrics et al., 2011; White & Cooley, 2018). The current HCT measure leaves out information about how youth and families are preparing for the transfer of care and youths' readiness to transition to an adult care setting. Youth HCT readiness is a well-developed field of study with many validated measures for the general population,

and youth with specific health conditions (Betz et al., 2021; Cheak-Zamora, Petroski, et al., 2020; Cheak-Zamora, Teti, & Tait, 2020; Ferris et al., 2012; Ferris et al., 2015; Sawicki et al., 2009). The inclusion of a youth readiness measure in national surveys would add an important layer to our understanding of HCT.

Furthermore, caregivers describe needing additional HCT services than what is currently being assessed in the national survey. These supplementary needs include support preparing youth for various aspects of adulthood, self-management skills, care coordination, finding a knowledgeable adult provider willing to take on a new patient, assistance navigating eligibility requirements for insurance and other service systems, and help to acquire accommodations in other areas of the person's life. The three components included in the 2016–2019 surveys (i.e. shift to an adult provider, private time with a provider, and gain skills or understanding health care changes) only touch on a few of these identified needs. In all, the NSCH includes 13 questions related to HCT services. If added to the HCT measure, the inclusion of some or all of these questions will improve the comprehensiveness and representativeness of the measure.

Allowing participants with missing data (legitimate skips) to be included in HCT outcome measures has been a consistent issue in the HCT outcome. In the current survey, participants can skip three out of four HCT questions and be designated as meeting the outcome. Specifically, if the youth "has at least one valid positive response to any of these components and the remainder of the components were missing or legitimately skipped" they are categorized as meeting the HCT criteria (US Census Bureau, 2018). It is unclear the number of participants that fail to answer one or more of the HCT questions, but this could have a profound effect on the number of participants identified as achieving the outcome measure. Future studies should report the number of participants with one, two, or three skipped HCT questions and utilize alternative coding methods to reclassify participants with multiple missing responses.

Finally, the HCT outcome measure has not been validated in any of the national studies. The MCHB utilized a panel of experts to re-examine the existing HCT question, decide on the best composite measure (Outcome 6) to be used in the 2016 survey, and recommend future measurement considerations. The ideal next step is to develop a comprehensive measure of HCT service provision using advanced statistical analysis to identify model fitness and examine the validity of the measure. Examining the model fit of the various HCT questions would ensure that all relevant variables are included in the outcome measure. This would likely broaden our definition of what HCT services should be and lead to better representation of the needs of youth and their families during the transition to adulthood and an adult model of care. Additionally, it would be valuable to convene a panel of experts that are representative of a broad constituency of stakeholders including self-advocates, family members, interdisciplinary researchers, and clinical experts with recognized HCT expertise.

## Conclusion

This literature review aims to synthesize the use of HCT measures in the most utilized national studies on children's health. Remarkably, HCT services have been assessed in national surveys for nearly 20 years. Having a consistent measure of HCT provision has improved our understanding of how, where, and to whom these services are provided. The use of the HCT outcome measure in Title V programming has led to the popularization of the topic and wide utilization of this and other HCT measures in public and private clinic settings (Kogan et al., 2015; Maternal and Child Health Bureau, 2021). The full implementation of HCT services has the potential to increase the quality of care, improve patient access to needed services, reduce clinic over-crowding, and move pediatric clinics closer to medical home standards (Gray et al., 2018; Lotstein et al., 2009; Schmidt et al., 2020).

Continued utilization of the HCT outcome measure in the NSCH will lead to a better understanding of clinical care. The new methodology of the NSCH allows for comparisons between youth with typical development and those with varying physical, mental, and developmental disabilities. The annual data collection and distribution method will also add to the continued and timely understanding of this and other quality of care measures. Future inclusion of other HCT questions and validation of the HCT outcome measure is recommended to promote continued and extensive use of a measure that represents the broad needs of youth and their families.

### Author statement

Nancy Cheak-Zamora: Conceptualization, Writing- Original draft preparation, Data analysis, Writing- Reviewing and Editing, and Funding acquisition.

Cecily Betz: Conceptualization, Writing- Original draft, and Reviewing and Editing.

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Authors have in direct or indirect conflicts of interest or disclosures to report.

### References

- American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians (2011). Supporting the health care transition from adolescence to adulthood in the medical home *128*(1), 182–200. <https://doi.org/10.1542/peds.2011-0969>.
- American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians-American Society of Internal Medicine (2002). A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*, *110*(6), 1304–1306.
- Beresford, B., Moran, N., Sloper, P., Cusworth, L., Mitchell, W., Spiers, G., ... Beecham, J. (2013). *Transition to adult services and adulthood for young people with autistic Spectrum conditions (working paper no: DH 2525, Department of Health Policy Research Programme Project reference no. 016 0108, final report)*.
- Betz, C. L. (2017). SPN position statement: Transition of pediatric patients into adult care. *Journal of Pediatric Nursing*, *35*, 160–164.
- Betz, C. L., Coyne, I., & Hudson, S. H. (2021). Health care transition: The struggle to define itself, comprehensive child and adolescent nursing. *Journal of Pediatric Nursing* (Online ahead of print).
- Betz, C. L., O'Kane, L. S., Nehring, W. M., & Lobo, M. L. (2016). Systematic review: Health care transition practice service models. *Nursing Outlook*, *64*(3), 229–243. <https://doi.org/10.1016/j.outlook.2015.12.011>.
- Blackman, J. A., & Conaway, M. R. (2014). Adolescents with cerebral palsy: Transitioning to adult health care services. *Clinical Pediatrics*, *53*(4), 356–363. <https://doi.org/10.1177/000922813510203>.
- Blum, R. W. (1995). Transition to adult health care: Setting the stage. *The Journal of Adolescent Health: Official Publication of the Society for Adolescent Medicine*, *17*(1), 3–5. [https://doi.org/10.1016/1054-139X\(95\)00073-2](https://doi.org/10.1016/1054-139X(95)00073-2).
- Blum, R. W., Garell, D., Hodgman, C. H., Jorissen, T. W., Okinow, N. A., Orr, D. P., & Slap, G. B. (1993). Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *The Journal of Adolescent Health: Official Publication of the Society for Adolescent Medicine*, *14*(7), 570–576.
- Blumberg, S. J. (2003). *Design and operation of the national survey of children with special health care needs, 2001*.
- Blumberg, S. J., Welch, E. M., Chowdhury, S. R., Upchurch, H. L., Parker, E. K., & Skalland, B. J. (2008). Design and operation of the National Survey of children with special health care needs, 2005–2006. *Vital and health statistics. Ser. 1, Programs and Collection Procedures*. 45. (pp. 1–188).
- Census Bureau, U. S. (2019). 2018 National Survey of Children's Health Methodology Report. <https://www2.census.gov/programs-surveys/nsch/technical-documentation/methodology/2018-NSCH-Methodology-Report.pdf>.
- Cheak-Zamora, N., Petroski, G., La Manna, A., Beversdorf, D., & Farmer, J. (2020). Validation of the health-related Independence for young adults with autism Spectrum disorder measure-caregiver version. *Journal of Autism and Developmental Disorders*, 1–11.
- Cheak-Zamora, N., Teti, M., & Tait, A. (2020). Development and initial testing of a health-related Independence measure for autistic young adults as reported by caregivers. *Autism in Adulthood*, *2*(3), 255–267. <https://doi.org/10.1089/aut.2019.0072>.
- Cheak-Zamora, N. C., & Farmer, J. E. (2015). The impact of the medical home on access to care for children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *45*(3), 636–644.
- Cheak-Zamora, N. C., & Teti, M. (2015). "You think it's hard now... it gets much harder for our children": Youth with autism and their caregiver's perspectives of health care transition services. *Autism*, *19*(8), 992–1001.
- Cheak-Zamora, N. C., Teti, M., & First, J. (2015). "Transitions are scary for our kids, and They're scary for us": Family member and youth perspectives on the challenges of transitioning to adulthood with autism. *Journal of Applied Research in Intellectual Disabilities*, *28*(6), 548–560.
- Cheak-Zamora, N. C., & Thullen, M. (2017). Disparities in quality and access to care for children with developmental disabilities and multiple health conditions. *Maternal and Child Health Journal*, *21*(1), 36–44.
- Cheak-Zamora, N. C., Yang, X., Farmer, J. E., & Clark, M. (2013). Disparities in transition planning for youth with autism spectrum disorder. *Pediatrics*, *131*(3), 447–454.
- Child and Adolescent Health Measurement Initiative (2021). *2005/06 National Survey of children with special health care needs*. Data Resource Center for Child and Adolescent Health. [www.cshcnadata.org](http://www.cshcnadata.org).
- Downing, K. F., Oster, M. E., & Farr, S. (2017). Preparing adolescents with heart problems for transition to adult care, 2009–2010 National Survey of Children with Special Health Care Needs: DOWNING et al. *Congenital Heart Disease*, *12*(4), 497–506. <https://doi.org/10.1111/chd.12476>.
- Duke, N. N., & Scal, P. B. (2011). Adult care transitioning for adolescents with special health care needs: A pivotal role for family centered care. *Maternal and Child Health Journal*, *15*(1), 98–105.
- Federal Partners in Transition Strategic Planning Committee (2015). *The 2020 federal youth transition plan: A federal interagency strategy*. Washington, DC: US Department of Labor, Office of Disability Employment Policy.
- Ferris, M., Cohen, S., Haberman, C., Javalkar, K., Massengill, S., Mahan, J. D., ... Medeiros, M. (2015). Self-management and transition readiness assessment: Development, reliability, and factor structure of the STARx questionnaire. *Journal of Pediatric Nursing*, *30*(5), 691–699.
- Ferris, M. E., Harward, D. H., Bickford, K., Layton, J. B., Ferris, M. T., Hogan, S. L., ... Hooper, S. R. (2012). A clinical tool to measure the components of health-care transition from pediatric care to adult care: The UNC TRANSITION scale. *Renal Failure*, *34*(6), 744–753.
- Foster, H. E., Minden, K., Clemente, D., Leon, L., McDonagh, J. E., Kamphuis, S., ... Waite-Jones, J. (2017). EULAR/PRIS standards and recommendations for the transitional care of young people with juvenile-onset rheumatic diseases. *Annals of the Rheumatic Diseases*, *76*(4), 639–646.
- Ghandour, R. M., Jones, J. R., Lebrun-Harris, L. A., Minnaert, J., Blumberg, S. J., Fields, J., ... Kogan, M. D. (2018). The design and implementation of the 2016 National Survey of Children's health. *Maternal and Child Health Journal*, *22*(8), 1093–1102. <https://doi.org/10.1007/s10995-018-2526-x>.
- Gray, D. J. P., Sidaway-Lee, K., White, E., Thorne, A., & Evans, P. H. (2018). Continuity of care with doctors—A matter of life and death? A systematic review of continuity of care and mortality. *BMJ Open*, *8*(6), Article e021161.
- Ilango, S. M., Lebrun-Harris, L. A., Jones, J. R., McManus, M. A., Cyr, M., Mann, M. Y., & White, P. H. (2021). Associations between health care transition preparation among youth in the US and other components of a well-functioning system of services. *The Journal of Adolescent Health*, *69*(3), 414–423. <https://doi.org/10.1016/j.jadohealth.2021.01.006>.
- Kane, D. J., Kasehagen, L., Punyko, J., Carle, A. C., Penziner, A., & Thorson, S. (2009). What factors are associated with state performance on provision of transition services to CSHCN? *Pediatrics*, *124*(Suppl. 4), S375–S383. <https://doi.org/10.1542/peds.2009-1255H>.
- Knapp, C. A., Madden, V. L., & Marcu, M. I. (2010). Factors that affect parent perceptions of provider-family partnership for children with special health care needs. *Maternal and Child Health Journal*, *14*(5), 742–750.
- Kogan, M. D., Dykton, C., Hirai, A. H., Strickland, B. B., Bethell, C. D., Naqvi, I., ... Lu, M. C. (2015). A new performance measurement system for maternal and child health in the United States. *Maternal and Child Health Journal*, *19*(5), 945–957.
- Le Roux, E., Mellerio, H., Guilmin-Crépon, S., Gottot, S., Jacquin, P., Boulkedid, R., & Albert, C. (2017). Methodology used in comparative studies assessing programmes of transition from paediatrics to adult care programmes: A systematic review. *BMJ Open*, *7*(1).
- 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*(4). <https://doi.org/10.1542/peds.2018-0194>.
- Leeb, R. T., Danielson, M. L., Bitsko, R. H., Cree, R. A., Godfred-Cato, S., Hughes, M. M., ... Lebrun-Harris, L. A. (2020). Support for transition from adolescent to adult health care among adolescents with and without mental, behavioral, and developmental disorders—United States, 2016–2017. *MMWR. Morbidity and Mortality Weekly Report*, *69*(34), 1156–1160. <http://dx.doi.org/10.15585/mmwr.mm6934a2>.

- Lestishock, L., Disabato, J., Daley, A., Cuomo, C., Seeley, A., & Chouteau, W. (2020). NAPNAP position statement on supporting the transition from pediatric to adult-focused health care. *Journal of Pediatric Health Care*, 34(4), 390–394.
- Lotstein, D. S., Ghandour, R., Cash, A., McGuire, E., Strickland, B., & Newacheck, P. (2009). Planning for health care transitions: Results from the 2005–2006 National Survey of children with special health care needs. *Pediatrics*, 123(1), e145–e152. <https://doi.org/10.1542/peds.2008-1298>.
- Lotstein, D. S., McPherson, M., Strickland, B., & Newacheck, P. W. (2005). Transition planning for youth with special health care needs: Results from the National Survey of children with special health care needs. *Pediatrics*, 115(6), 1562–1568. <https://doi.org/10.1542/peds.2004-1262>.
- Maternal and Child Health Bureau (2021). Maternal and child health bureau strategic plan: Full year 2003–2007. Retrieved January 10, 2021, from <http://mchb.hrsa.gov/research/documents/mchbstratplan0307>.
- Mazurek, M. O., Sadikova, E., Cheak-Zamora, N., Hardin, A., Huerta, I., Sohl, K., & Malow, B. A. (2021). They deserve the “same level of care that any other person deserves”: Caregiver perspectives on healthcare for adults on the autism spectrum. *Research in Autism Spectrum Disorders*, 89, Article 101862.
- 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(1), 63–73. <https://doi.org/10.1089/pop.2018.0027>.
- McManus, M., White, P., Barbour, A., Downing, B., Hawkins, K., Quion, N., ... McAllister, J. W. (2015). Pediatric to adult transition: A quality improvement model for primary care. *Journal of Adolescent Health*, 56(1), 73–78.
- McManus, M. A., Pollack, L. R., Cooley, W. C., McAllister, J. W., Lotstein, D., Strickland, B., & Mann, M. Y. (2013). Current status of transition preparation among youth with special needs in the United States. *Pediatrics*, 131(6), 1090. <https://doi.org/10.1542/peds.2012-3050>.
- McPherson, M., Weissman, G., Strickland, B. B., van Dyck, P. C., Blumberg, S. J., & Newacheck, P. W. (2004). Implementing community-based systems of services for children and youths with special health care needs: How well are we doing? *Pediatrics*, 113(5 Suppl), 1538–1544.
- Molner, C., Fioravanti, M. S., Rau, W., Bruch, K. A., & Bobo, N. (2019). *Transition planning for students with healthcare need. Position Statement*. Silver Spring, MD: National Association of School Nurses.
- Nishikawa, B. R., Daaleman, T. P., & Nageswaran, S. (2011). Association of Provider Scope of Practice With Successful Transition for Youth With Special Health Care Needs. *Journal of Adolescent Health*, 48(2), 209–211. <https://doi.org/10.1016/j.jadohealth.2010.06.011>.
- Nugent, J., Gorman, G., & Erdie-Lalena, C. R. (2018). Disparities in access to healthcare transition Services for Adolescents with down syndrome. *The Journal of Pediatrics*, 197, 214–220. <https://doi.org/10.1016/j.jpeds.2018.01.072>.
- Park, M. J., Adams, S. H., & Irwin, C. E. (2011). Health care services and the transition to young adulthood: Challenges and opportunities. *Academic Pediatrics*, 11(2), 115–122. <https://doi.org/10.1016/j.acap.2010.11.010>.
- Richmond, N., Tran, T., & Berry, S. (2011). Receipt of transition services within a medical home: Do racial and geographic disparities exist? *Maternal and Child Health Journal*, 15(6), 742–752.
- Richmond, N. E., Tran, T., & Berry, S. (2012). Can the medical home eliminate racial and ethnic disparities for transition services among youth with special health care needs? *Maternal and Child Health Journal*, 16(4), 824–833.
- Sawicki, G. S., Lukens-Bull, K., Yin, X., Demars, N., Huang, I.-C., Livingood, W., ... Wood, D. (2009). Measuring the transition readiness of youth with special healthcare needs: Validation of the TRAQ—Transition readiness assessment questionnaire. *Journal of Pediatric Psychology*, 36(2), 160–171. <https://doi.org/10.1093/jpepsy/jsp128>.
- Scal, P., & Ireland, M. (2005). Addressing transition to adult health care for adolescents with special health care needs. *Pediatrics*, 115(6), 1607–1612. <https://doi.org/10.1542/peds.2004-0458>.
- Scal, P., Horvath, K., & Garwick, A. (2009). Preparing for adulthood: Health care transition counseling for youth with arthritis. *Arthritis and Rheumatism*, 61(1), 52–57. <https://doi.org/10.1002/art.24088>.
- Schmidt, A., Ilango, S. M., McManus, M. A., Rogers, K. K., & White, P. H. (2020). Outcomes of pediatric to adult health care transition interventions: An updated systematic review. *Journal of Pediatric Nursing*, 51, 92–107. <https://doi.org/10.1016/j.pedn.2020.01.002>.
- Shattuck, P. T., Wagner, M., Narendorf, S., Sterzing, P., & Hensley, M. (2011). Post-high school service use among young adults with an autism spectrum disorder. *Archives of Pediatrics & Adolescent Medicine*, 165(2), 141–146.
- Strickland, B. B., Jones, J. R., Newacheck, P. W., Bethell, C. D., Blumberg, S. J., & Kogan, M. D. (2015). Assessing systems quality in a changing health care environment: The 2009–10 National Survey of children with special health care needs. *Maternal and Child Health Journal*, 19(2), 353–361. <https://doi.org/10.1007/s10995-014-1517-9>.
- Strickland, B. B., Van Dyck, P. C., Kogan, M. D., Lauver, C., Blumberg, S. J., Bethell, C. D., & Newacheck, P. W. (2011). Assessing and ensuring a comprehensive system of services for children with special health care needs: A public health approach. *American Journal of Public Health*, 101(2), 224–231.
- U.S. Census Bureau (2018). 2017 National Survey of Children's Health Methodology Report. <https://www.census.gov/content/dam/Census/programs-surveys/nsch/tech-documentation/methodology/2017-NSCH-Methodology-Report.pdf>.
- US Census Bureau (2018). *2016 National Survey of Children's Health: Methodology report*.
- US Department of Health and Human Services (2007). *The national survey of children with special health care needs chartbook 2005–2006*. Rockville, MD: Department of Health and Human Services.
- Walsh, C., Jones, B., & Schonwald, A. (2017). Health care transition planning among adolescents with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 47(4), 980–991.
- White, P. H., & Cooley, W. C. (2018). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*, 142(5), Article e20182587. <https://doi.org/10.1542/peds.2018-2587>.
- 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(6), 796–804. <https://doi.org/10.1007/s10995-019-02858-6>.
- Zeng, S., Strain, A., & Sung, C. (2021). Health care transition services and adaptive and social-emotional functioning of youth with autism Spectrum disorder. *Journal of Autism and Developmental Disorders*, 51(2), 589–599. <https://doi.org/10.1007/s10803-020-04564-7>.
- Zuckerman, K. E., Lindly, O. J., Bethell, C. D., & Kuhlthau, K. (2014). Family impacts among children with autism Spectrum disorder: The role of health care quality. *Academic Pediatrics*, 14(4), 398–407. <https://doi.org/10.1016/j.acap.2014.03.011>.