



## Measure Information

This document contains the information submitted by measure developers/stewards, but is organized according to NQF's measure evaluation criteria and process. The item numbers refer to those in the submission form but may be in a slightly different order here. In general, the item numbers also reference the related criteria (e.g., item 1b.1 relates to subcriterion 1b).

### Brief Measure Information

**NQF #:** 1340

**Corresponding Measures:**

**De.2. Measure Title:** Children with Special Health Care Needs (CSHCN) who Receive Services Needed for Transition to Adult Health Care

**Co.1.1. Measure Steward:** The Child and Adolescent Health Measurement Initiative

**De.3. Brief Description of Measure:** Whether children with special health care needs (CSHCN) ages 12-17 have doctors who usually/always encourage increasing responsibility for self-care AND (when needed) have discussed transitioning to adult health care, changing health care needs, and how to maintain insurance coverage

**1b.1. Developer Rationale:** Health care providers, public health professionals and population-based health analysts can all benefit from knowing whether or not children are receiving quality care. The measure is comprised of three components: discussion about change in health care needs, discussion of continuity of insurance coverage, and discussion about self-care responsibility. The measure of transition services allows the benefit of comparing care quality across populations or demographic groups.

**S.4. Numerator Statement:** Percentage of youth with special health care needs who receive services needed for transition to adult health care services

**S.7. Denominator Statement:** Children with special health care needs (CSHCN) age 12-17 years

**S.10. Denominator Exclusions:** Excluded from denominator if child does not fall in target population age range of 12-17 years and/or if child does not have one or more special health care needs (non-CSHCN).

**De.1. Measure Type:** Outcome

**S.23. Data Source:** Instrument-Based Data

**S.26. Level of Analysis:** Other, Population : Regional and State

**IF Endorsement Maintenance – Original Endorsement Date:** Aug 15, 2011 **Most Recent Endorsement Date:** Aug 15, 2011

**IF this measure is included in a composite, NQF Composite#/title:**

**IF this measure is paired/grouped, NQF#/title:**

**De.4. IF PAIRED/GROUPED, what is the reason this measure must be reported with other measures to appropriately interpret results?**

### 1. Evidence, Performance Gap, Priority – Importance to Measure and Report

Extent to which the specific measure focus is evidence-based, important to making significant gains in healthcare quality, and improving health outcomes for a specific high-priority (high-impact) aspect of healthcare where there is variation in or overall less-than-optimal performance. **Measures must be judged to meet all subcriteria to pass this criterion and be evaluated against the remaining criteria.**

**1a. Evidence to Support the Measure Focus – See attached Evidence Submission Form**  
1340\_Evidence\_MSF5.0\_Data.doc

**1b. Performance Gap**

Demonstration of quality problems and opportunity for improvement, i.e., data demonstrating:

- considerable variation, or overall less-than-optimal performance, in the quality of care across providers; and/or
- disparities in care across population groups.

**1b.1. Briefly explain the rationale for this measure** (e.g., the benefits or improvements in quality envisioned by use of this measure) Health care providers, public health professionals and population-based health analysts can all benefit from knowing whether or not children are receiving quality care. The measure is comprised of three components: discussion about change in health care needs, discussion of continuity of insurance coverage, and discussion about self-care responsibility. The measure of transition services allows the benefit of comparing care quality across populations or demographic groups.

**1b.2. Provide performance scores on the measure as specified (current and over time) at the specified level of analysis.** (This is required for endorsement maintenance. Include mean, std dev, min, max, interquartile range, scores by decile. Describe the data source including number of measured entities; number of patients; dates of data; if a sample, characteristics of the entities included). This information also will be used to address the subcriterion on improvement (4b.1) under Usability and Use.

In the 2005/06 survey, only 41.2% of CSHCN age 12-17 years received the necessary guidance on transition to adult health care services nationally.

In the 2009/10 survey, 40.0% of CSHCN age 12-17 years received the necessary guidance on transition to adult health care services nationally.

New data will be available in July 2017.

**1b.3. If no or limited performance data on the measure as specified is reported in 1b2, then provide a summary of data from the literature that indicates opportunity for improvement or overall less than optimal performance on the specific focus of measurement.**

Child and Adolescent Health Measurement Initiative. 2005/06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. [www.cshcndata.org](http://www.cshcndata.org)

**1b.4. Provide disparities data from the measure as specified (current and over time) by population group, e.g., by race/ethnicity, gender, age, insurance status, socioeconomic status, and/or disability.** (This is required for endorsement maintenance. Describe the data source including number of measured entities; number of patients; dates of data; if a sample, characteristics of the entities include.) This information also will be used to address the subcriterion on improvement (4b.1) under Usability and Use.

From the 2005/06 survey:

Children living in a lower income household (0-199% FPL; 29.6%) are less likely to receive Transition to Adulthood Services than children living in a higher income household (400% FPL or more; 53.7%).

Uninsured children are the least likely to receive Transition to Adulthood Services (18.2%), followed by publicly insured children (27.5%) and privately insured children (49.1%).

Children whose condition is controlled by Prescription Medication only are more likely to receive transition services (49.9%), followed by Prescription Medication and Elevated Service Use (42.0%), Elevated Service Use only (31.6%), and Functional Limitations (29.9%).

Children with a strong parent-provider partnership were over 5 times more likely to receive transition services compared to those without (OR: 5.07).

From the 2009/19 survey:

Children living in a lower income household (0-199% FPL; 28.4%) are less likely to receive Transition to Adulthood Services than children living in a higher income household (400% FPL or more; 52.2%).

Uninsured children are the least likely to receive Transition to Adulthood Services (19.6%), followed by publicly insured children (25.8%) and privately insured children (50.2%).

Children whose condition is controlled by Prescription Medication only are more likely to receive transition services (51.4%),

followed by Prescription Medication and Elevated Service Use (40.2%), Elevated Service Use only (27.7%), and Functional Limitations (26.2%).

**1b.5. If no or limited data on disparities from the measure as specified is reported in 1b4, then provide a summary of data from the literature that addresses disparities in care on the specific focus of measurement. Include citations.**

Child and Adolescent Health Measurement Initiative. 2009/10 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. [www.childhealthdata.org](http://www.childhealthdata.org)

Knapp CA, Madden VL, Marcu MI. Factors that Affect Parent Perceptions of Provider-Family Partnership for Children with Special Health Care Needs. *Maternal & Child Health Journal*, 2010, 14:742–750.

**1c. High Priority** (previously referred to as High Impact)

The measure addresses:

- a specific national health goal/priority identified by DHHS or the National Priorities Partnership convened by NQF; OR
- a demonstrated high-priority (high-impact) aspect of healthcare (e.g., affects large numbers of patients and/or has a substantial impact for a smaller population; leading cause of morbidity/mortality; high resource use (current and/or future); severity of illness; and severity of patient/societal consequences of poor quality).

**1c.1. Demonstrated high priority aspect of healthcare**

Patient/societal consequences of poor quality

**1c.2. If Other:**

**1c.3. Provide epidemiologic or resource use data that demonstrates the measure addresses a high priority aspect of healthcare.**

List citations in 1c.4.

According to the MCHB, all youth with special health care needs should receive the services necessary to make appropriate transitions to adult health care, work and independence.

Youth with Special Health Care Needs (YSHCN) who transition without specific transition services are more likely to have poor outcomes compared to their peers, including insurance inconsistency, higher rates of hospitalization and advanced care, and not achieving adult social roles.

Two-thirds of CSHCN experience at least one adverse transition events: (1) do not have a usual source of care, (2) unmet need for health care, (3) delay in care the last 6 months, (4) uninsured or inconsistency in insurance coverage. Therefore, this is a critical issue to address through Transition to Adulthood Services to help CSHCN successfully transfer into young adulthood.

**1c.4. Citations for data demonstrating high priority provided in 1a.3**

Child and Adolescent Health Measurement Initiative. 2009/10 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. [www.childhealthdata.org](http://www.childhealthdata.org)

Salkever D. Activity status, life satisfaction and perceived productivity for young adults with developmental disabilities. *Journal of Rehabilitation*. 2000;66(3):4-13.

Van Naarden Braun K, Yeargin-Allsop M, Lollar D. A multidimensional approach to the transition of children with developmental disabilities into young adulthood: The acquisition of adult social roles. *Disability and Rehabilitation* 2006; 28(15): 915-926.

Lotstein DS, Inkelas M, Hays RD, Halfon N, Brook R. Access to care for youth with special health care needs in the transition to adulthood. *Journal of Adolescent Health*. 2008, 43(1):23-9.

**1c.5. If a PRO-PM (e.g. HRQoL/functional status, symptom/burden, experience with care, health-related behaviors), provide evidence that the target population values the measured PRO and finds it meaningful. (Describe how and from whom their input was obtained.)**

## 2. Reliability and Validity—Scientific Acceptability of Measure Properties

Extent to which the measure, as specified, produces consistent (reliable) and credible (valid) results about the quality of care when implemented. **Measures must be judged to meet the subcriteria for both reliability and validity to pass this criterion and be evaluated against the remaining criteria.**

**2a.1. Specifications** The measure is well defined and precisely specified so it can be implemented consistently within and across organizations and allows for comparability. eMeasures should be specified in the Health Quality Measures Format (HQMF) and the Quality Data Model (QDM).

**De.5. Subject/Topic Area** (check all the areas that apply):

**De.6. Non-Condition Specific** (check all the areas that apply):

Access to Care, Care Coordination, Health and Functional Status : Change

**S.1. Measure-specific Web Page** (Provide a URL link to a web page specific for this measure that contains current detailed specifications including code lists, risk model details, and supplemental materials. Do not enter a URL linking to a home page or to general information.)

<http://www.cdc.gov/nchs/data/slaits/NSCSHCNIIEnglishQuest.pdf>

**S.2a. If this is an eMeasure**, HQMF specifications must be attached. Attach the zipped output from the eMeasure authoring tool (MAT) - if the MAT was not used, contact staff. (Use the specification fields in this online form for the plain-language description of the specifications)

This is not an eMeasure Attachment:

**S.2b. Data Dictionary, Code Table, or Value Sets** (and risk model codes and coefficients when applicable) must be attached. (Excel or csv file in the suggested format preferred - if not, contact staff)

URL Attachment:

**S.3. For endorsement maintenance**, please briefly describe any changes to the measure specifications since last endorsement date and explain the reasons.

No changes to specifications.

**S.4. Numerator Statement** (Brief, narrative description of the measure focus or what is being measured about the target population, i.e., cases from the target population with the target process, condition, event, or outcome)

IF an OUTCOME MEASURE, state the outcome being measured. Calculation of the risk-adjusted outcome should be described in the calculation algorithm.

Percentage of youth with special health care needs who receive services needed for transition to adult health care services

**S.5. Time Period for Data** (What is the time period in which data will be aggregated for the measure, e.g., 12 mo, 3 years, look back to August for flu vaccination? Note if there are different time periods for the numerator and denominator.)

Encounter or point in time.

**S.6. Numerator Details** (All information required to identify and calculate the cases from the target population with the target process, condition, event, or outcome such as definitions, specific data collection items/responses, code/value sets – Note: lists of individual codes with descriptors that exceed 1 page should be provided in an Excel or csv file in required format at S.2b)

IF an OUTCOME MEASURE, describe how the observed outcome is identified/counted. Calculation of the risk-adjusted outcome should be described in the calculation algorithm.

For a child to be included in the numerator of receiving services needed to transition to adulthood, criteria from the following must be met:

-Child must qualify as having one or more special health care needs

-Doctors usually/always encourage increasing responsibility for self-care (C6Q08)

-If child's doctor only treats children, then doctor had conversation with child about eventually seeing other health care providers who treat adults (C6Q0A\_B), if needed

-Doctor discussed changing health care needs as youth becomes adult (C6Q0A), if needed

-Doctor discussed insurance coverage as youth becomes adult (C6Q0A\_E), if needed

**S.7. Denominator Statement** (Brief, narrative description of the target population being measured)

Children with special health care needs (CSHCN) age 12-17 years

**S.8. Target Population Category** (Check all the populations for which the measure is specified and tested if any):

Children

**S.9. Denominator Details** (All information required to identify and calculate the target population/denominator such as definitions, specific data collection items/responses, code/value sets – Note: lists of individual codes with descriptors that exceed 1 page should be provided in an Excel or csv file in required format at S.2b)

Children with special health care needs (CSHCN) age 12-17 years

**S.10. Denominator Exclusions** (Brief narrative description of exclusions from the target population)

Excluded from denominator if child does not fall in target population age range of 12-17 years and/or if child does not have one or more special health care needs (non-CSHCN).

**S.11. Denominator Exclusion Details** (All information required to identify and calculate exclusions from the denominator such as definitions, specific data collection items/responses, code/value sets – Note: lists of individual codes with descriptors that exceed 1 page should be provided in an Excel or csv file in required format at S.2b)

If child is older than 17 years of age, excluded from denominator.

If child is younger than 12 years, excluded from denominator.

CSHCN are defined by the standardized and validated CSHCN Screener. The screener is administered at the beginning of the survey and all remaining items in the survey are only asked regarding a child with special health care needs.

**S.12. Stratification Details/Variables** (All information required to stratify the measure results including the stratification variables, definitions, specific data collection items/responses, code/value sets – Note: lists of individual codes with descriptors that exceed 1 page should be provided in an Excel or csv file in required format with at S.2b)

No stratification is required.

When the Transition to Adulthood measure was administered in its most recent form, in the 2009/10 National Survey of Children with Special Health Care Needs, the survey included a number of child demographic variables that allow for stratification of the findings by possible vulnerability:

- Age
- Gender
- Geographic location- State, HRSA Region, National level Rural Urban Commuter Areas (RUCA)
- Race/ethnicity
- Health insurance- type, consistency
- Primary household language
- Household income
- Type of Special Health Care Need

**S.13. Risk Adjustment Type** (Select type. Provide specifications for risk stratification in S.12 and for statistical model in S.14-15)

No risk adjustment or risk stratification

If other:

**S.14. Identify the statistical risk model method and variables** (Name the statistical method - e.g., logistic regression and list all the risk factor variables. Note - risk model development and testing should be addressed with measure testing under Scientific Acceptability)

**S.15. Detailed risk model specifications** (must be in attached data dictionary/code list Excel or csv file. Also indicate if available at measure-specific URL identified in S.1.)

Note: Risk model details (including coefficients, equations, codes with descriptors, definitions), should be provided on a separate

worksheet in the suggested format in the Excel or csv file with data dictionary/code lists at S.2b.

**S.15a. Detailed risk model specifications** (if not provided in excel or csv file at S.2b)

**S.16. Type of score:**

Rate/proportion

If other:

**S.17. Interpretation of Score** (Classifies interpretation of score according to whether better quality is associated with a higher score, a lower score, a score falling within a defined interval, or a passing score)

Better quality = Higher score

**S.18. Calculation Algorithm/Measure Logic** (Describe the calculation of the measure score as an ordered sequence of steps including identifying the target population; exclusions; cases meeting the target process, condition, event, or outcome; aggregating data; risk adjustment; etc.)

To receive numerator of child receiving services needed to transition to adulthood, youth must meet all 4 criteria:

-If child's doctor only treats children (C6Q07=1), then doctor had conversation with child about eventually seeing other health care providers who treat adults (C6Q0A\_B=0), or the discussion would not have been helpful (C6Q0A\_C=0).

-Doctor discussed changing health care needs as youth becomes adult (C6Q0A=1), or the discussion would not have been helpful (C6Q0A\_D=0)

-Doctor discussed insurance coverage as youth becomes adult (C6Q0A\_E=1), or the discussion would not have been helpful (C6Q0A\_F)

-Doctor usually or always encourage youth to engage in appropriate self-care, such as taking medications, understanding his/her diagnosis, or following medical advice (C6Q08=3 or 4)

**S.19. Calculation Algorithm/Measure Logic Diagram URL or Attachment** (You also may provide a diagram of the Calculation Algorithm/Measure Logic described above at measure-specific Web page URL identified in S.1 OR in attached appendix at A.1)

**S.20. Sampling** (If measure is based on a sample, provide instructions for obtaining the sample and guidance on minimum sample size.)

IF a PRO-PM, identify whether (and how) proxy responses are allowed.

Best guideline to follow is the survey methodology used in the 2009/2010 National Survey of Children with Special Health Care Needs (NS-CSHCN). The NS-CSHCN first uses the sampling frame generated in the process of data collection for the National Immunization Survey (NIS). Once it is determined whether a child is present in the household and whether or not they are age eligible for the NIS, it is then determined whether the child may also be eligible for the NS-CSHCN.

The goal of the NS-CSHCN sample design was to generate samples representative of populations of children with special health care needs within each state. An additional goal of the NS-CSHCN was to obtain state-specific sample sizes that were sufficiently large to permit reasonably precise estimates of the health characteristics of CSHCN in each state.

To achieve these goals, state samples were designed to obtain a minimum of 750 completed interviews. The number of children to be selected in each NIS estimation area was determined by allocating the total of 750 CSHCN in the state to each NIS estimation area within the state in proportion to the total estimated number of households with children in the NIS estimation area. Given this allocation, the number of households that needed to be screened in each NIS estimation area was calculated using the expected proportion of households with children under 18 years of age in the area. Then, the number of telephone numbers that needed to be called was computed using the expected working residential number rate, adjusted for expected nonresponse.

A total of 40,242 interviews were completed from July 2009 to March 2011 for the 2009/2010 National Survey of Children with Special Health Care Needs. A random-digit-dialed sample of households with children less than 18 years of age was selected from each of the 50 states and the District of Columbia. All children residing in the household under 18 years of age were screened for special health care needs using the validated CSHCN Screener. If more than one child in the household was identified with special needs, only one child with special health care needs was randomly selected to be the subject of the survey. The respondent was a

parent or guardian who knew about the child's health and health care.

**S.21. Survey/Patient-reported data** (If measure is based on a survey, provide instructions for conducting the survey and guidance on minimum response rate.)

IF a PRO-PM, specify calculation of response rates to be reported with performance measure results.

[http://www.cdc.gov/nchs/data/slaits/NS\\_CSHCN\\_Questionnaire\\_09\\_10.pdf](http://www.cdc.gov/nchs/data/slaits/NS_CSHCN_Questionnaire_09_10.pdf) and

[http://www.childhealthdata.org/docs/drc/200910-cshcn-spss-codebook\\_final\\_051012.pdf?sfvrsn=1](http://www.childhealthdata.org/docs/drc/200910-cshcn-spss-codebook_final_051012.pdf?sfvrsn=1)

**S.22. Missing data** (specify how missing data are handled, e.g., imputation, delete case.)

Required for Composites and PRO-PMs.

Unknown values (responses coded as 'refused', 'don't know', or system missing) are not included in the denominator when calculating prevalence estimates and weighted population counts displayed in the data query results table. In nearly every case, the proportion of unknown values is less than 1% and the exclusion of these values does not change the prevalence estimates (%) and only marginally affects the weighted population counts (Weighted Est.). Exceptions are noted in the form of a "Data Alert" at the bottom of a results table.

**S.23. Data Source** (Check ONLY the sources for which the measure is SPECIFIED AND TESTED).

If other, please describe in S.24.

Instrument-Based Data

**S.24. Data Source or Collection Instrument** (Identify the specific data source/data collection instrument e.g. name of database, clinical registry, collection instrument, etc.)

IF a PRO-PM, identify the specific PROM(s); and standard methods, modes, and languages of administration.

2009/10 National Survey of Children with Special Health Care Needs

**S.25. Data Source or Collection Instrument** (available at measure-specific Web page URL identified in S.1 OR in attached appendix at A.1)

Available at measure-specific web page URL identified in S.1

**S.26. Level of Analysis** (Check ONLY the levels of analysis for which the measure is SPECIFIED AND TESTED)

Other, Population : Regional and State

**S.27. Care Setting** (Check ONLY the settings for which the measure is SPECIFIED AND TESTED)

Other

If other: Applies to any care setting in which child receives care. Can stratify by usual source of care.

**S.28. COMPOSITE Performance Measure** - Additional Specifications (Use this section as needed for aggregation and weighting rules, or calculation of individual performance measures if not individually endorsed.)

**2a. Reliability** – See attached Measure Testing Submission Form

**2b. Validity** – See attached Measure Testing Submission Form

[1340\\_MeasureTesting\\_MSF5.0\\_Data.doc](#)

### 3. Feasibility

Extent to which the specifications including measure logic, require data that are readily available or could be captured without undue burden and can be implemented for performance measurement.

#### 3a. Byproduct of Care Processes

For clinical measures, the required data elements are routinely generated and used during care delivery (e.g., blood pressure, lab test, diagnosis, medication order).

##### 3a.1. Data Elements Generated as Byproduct of Care Processes.



Other

If other: [Survey](#)

### 3b. Electronic Sources

The required data elements are available in electronic health records or other electronic sources. If the required data are not in electronic health records or existing electronic sources, a credible, near-term path to electronic collection is specified.

**3b.1. To what extent are the specified data elements available electronically in defined fields?** (*i.e., data elements that are needed to compute the performance measure score are in defined, computer-readable fields*)

[ALL data elements are in defined fields in a combination of electronic sources](#)

**3b.2. If ALL the data elements needed to compute the performance measure score are not from electronic sources, specify a credible, near-term path to electronic capture, OR provide a rationale for using other than electronic sources.**

**3b.3. If this is an eMeasure, provide a summary of the feasibility assessment in an attached file or make available at a measure-specific URL.**

**Attachment:**

### 3c. Data Collection Strategy

Demonstration that the data collection strategy (e.g., source, timing, frequency, sampling, patient confidentiality, costs associated with fees/licensing of proprietary measures) can be implemented (e.g., already in operational use, or testing demonstrates that it is ready to put into operational use). For eMeasures, a feasibility assessment addresses the data elements and measure logic and demonstrates the eMeasure can be implemented or feasibility concerns can be adequately addressed.

**3c.1. Describe what you have learned/modified as a result of testing and/or operational use of the measure regarding data collection, availability of data, missing data, timing and frequency of data collection, sampling, patient confidentiality, time and cost of data collection, other feasibility/implementation issues.**

**IF a PRO-PM, consider implications for both individuals providing PROM data (patients, service recipients, respondents) and those whose performance is being measured.**

[Items are well understood and easy to implement. Items yield very low levels of missing values, don't know or refused answers.](#)

**3c.2. Describe any fees, licensing, or other requirements to use any aspect of the measure as specified** (*e.g., value/code set, risk model, programming code, algorithm*).

## 4. Usability and Use

Extent to which potential audiences (e.g., consumers, purchasers, providers, policy makers) are using or could use performance results for both accountability and performance improvement to achieve the goal of high-quality, efficient healthcare for individuals or populations.

### 4a. Accountability and Transparency

Performance results are used in at least one accountability application within three years after initial endorsement and are publicly reported within six years after initial endorsement (or the data on performance results are available). If not in use at the time of initial endorsement, then a credible plan for implementation within the specified timeframes is provided.

#### 4.1. Current and Planned Use

*NQF-endorsed measures are expected to be used in at least one accountability application within 3 years and publicly reported within 6 years of initial endorsement in addition to performance improvement.*

| Planned   | Current Use (for current use provide URL)   |
|---|---|
| <a href="#">Quality Improvement (Internal to the specific organization)</a> | <a href="#">Public Reporting</a><br><a href="#">Data Resource Center for Child and Adolescent Health</a><br><a href="http://childhealthdata.org/">http://childhealthdata.org/</a> |



|  |  |
|--|--|
|  | <p>Public Health/Disease Surveillance<br/> Publication: Transition Care for Children With Special Health Care Needs<br/> <a href="http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4533283/">http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4533283/</a><br/> <a href="http://www.ncbi.nlm.nih.gov/pubmed/24602574">http://www.ncbi.nlm.nih.gov/pubmed/24602574</a><br/> Publication: Transition care: future directions in education, health policy, and outcomes research.</p> |
|--|--|

**4a.1. For each CURRENT use, checked above, provide:**

- Name of program and sponsor
- Purpose
- Geographic area and number and percentage of accountable entities and patients included

Data Resource Center for Child and Adolescent Health sponsored by the National Maternal and Child Health Bureau: Public reporting and public health surveillance at [www.childhealthdata.org](http://www.childhealthdata.org) for use by policymakers, MCH program leaders and professionals, family and child health advocates, and researchers in order to inform and advance key national and state child and youth health goals. National and state-level reporting for all of the United States.

Public health disease surveillance via multiple journal publications.

The National Maternal and Child Health Bureau uses this measure as a Maternal and Child Health Title V Block grant national performance measure for state-level reporting. It is part of a set of performance measures that are key to understanding the impact of State Title V strategies and activities.

This measure is the official data source for tracking progress related to Healthy People 2020 (sponsored by U.S. Department of Health and Human Services) measure DH-5. National and state-level reporting for all of the United States.

**4a.2. If not currently publicly reported OR used in at least one other accountability application (e.g., payment program, certification, licensing) what are the reasons? (e.g., Do policies or actions of the developer/steward or accountable entities restrict access to performance results or impede implementation?)**

**4a.3. If not currently publicly reported OR used in at least one other accountability application, provide a credible plan for implementation within the expected timeframes -- any accountability application within 3 years and publicly reported within 6 years of initial endorsement. (Credible plan includes the specific program, purpose, intended audience, and timeline for implementing the measure within the specified timeframes. A plan for accountability applications addresses mechanisms for data aggregation and reporting.)**

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**4b. Improvement**

Progress toward achieving the goal of high-quality, efficient healthcare for individuals or populations is demonstrated. If not in use for performance improvement at the time of initial endorsement, then a credible rationale describes how the performance results could be used to further the goal of high-quality, efficient healthcare for individuals or populations.

**4b.1. Progress on Improvement. (Not required for initial endorsement unless available.)**

Performance results on this measure (current and over time) should be provided in 1b.2 and 1b.4. Discuss:

- Progress (trends in performance results, number and percentage of people receiving high-quality healthcare)
- Geographic area and number and percentage of accountable entities and patients included

No statistically significant changes: 41.2% (95% CI: 39.9 - 42.5%) met this measure in 2005/06 and 40.0% (95% CI: 38.7 - 41.4) met this measure in 2009/10. This is an outcome measure for which it takes time to see improvement, which is why it's important to continue to monitor it into the future.

**4b.2. If no improvement was demonstrated, what are the reasons? If not in use for performance improvement at the time of initial endorsement, provide a credible rationale that describes how the performance results could be used to further the goal of high-quality, efficient healthcare for individuals or populations.**

Due to the reasons previously stated, this measure is a key outcome for children and youth with special health care needs and a performance measure for the Maternal and Child Health Bureau Title V Block Grant and Healthy People 2020. Although there were no statistically significant changes at the national level, it is important to continue monitoring this measure at the state and local level to see what proportion of CSHCN are getting the support needed to transition to adult care and if interventions designed to improve this aspect of care for CSHCN are having the desired effects.

#### 4c. Unintended Consequences

The benefits of the performance measure in facilitating progress toward achieving high-quality, efficient healthcare for individuals or populations outweigh evidence of unintended negative consequences to individuals or populations (if such evidence exists).

**4c.1. Were any unintended negative consequences to individuals or populations identified during testing; OR has evidence of unintended negative consequences to individuals or populations been reported since implementation? If so, identify the negative unintended consequences and describe how benefits outweigh them or actions taken to mitigate them.**

No unintended consequences.

### 5. Comparison to Related or Competing Measures

If a measure meets the above criteria and there are endorsed or new related measures (either the same measure focus or the same target population) or competing measures (both the same measure focus and the same target population), the measures are compared to address harmonization and/or selection of the best measure.

#### 5. Relation to Other NQF-endorsed Measures

Are there related measures (conceptually, either same measure focus or target population) or competing measures (conceptually both the same measure focus and same target population)? If yes, list the NQF # and title of all related and/or competing measures.

Yes

##### 5.1a. List of related or competing measures (selected from NQF-endorsed measures)

2789 : Adolescent Assessment of Preparation for Transition (ADAPT) to Adult-Focused Health Care

##### 5.1b. If related or competing measures are not NQF endorsed please indicate measure title and steward.

Adolescent Assessment of Preparation for Transition (ADAPT) to Adult-Focused Health Care (2789)

#### 5a. Harmonization

The measure specifications are harmonized with related measures;

**OR**

The differences in specifications are justified

##### 5a.1. If this measure conceptually addresses EITHER the same measure focus OR the same target population as NQF-endorsed measure(s):

**Are the measure specifications completely harmonized?**

No

##### 5a.2. If the measure specifications are not completely harmonized, identify the differences, rationale, and impact on interpretability and data collection burden.

Although these measures are conceptually similar, the populations, data collection methods and specifications all differ. Measure 1340 is for CSHCN age 12-17 years and based on a parent reported survey while measure 2789 is for children with a chronic health condition ages 16-17 years and based on self-report. Measure 1340 measure the percent of CSHCN age 12-17 whose doctors usually/always encourage increasing responsibility for self-care AND (when needed) have discussed transitioning to adult health care, changing health care needs, and how to maintain insurance coverage while measure 2789 is an entire survey that measures 1) Counseling on Transition Self-Management, 2) Counseling on Prescription Medication, and 3) Transfer Planning. Therefore, these measures have differing constructs and uses. The ADAPT measure focuses on the quality of health care transition preparation based on youth reports. Alternatively, the CAHMI focuses on whether or not these aspects of transitioning are present. The CAHMI level of focus is national, regional and state whereas ADAPT is on the level of clinician, facility and health plan.

#### 5b. Competing Measures

The measure is superior to competing measures (e.g., is a more valid or efficient way to measure);

**OR**

Multiple measures are justified.

**5b.1. If this measure conceptually addresses both the same measure focus and the same target population as NQF-endorsed measure(s):**

**Describe why this measure is superior to competing measures (e.g., a more valid or efficient way to measure quality); OR provide a rationale for the additive value of endorsing an additional measure. (Provide analyses when possible.)**

### Appendix

**A.1 Supplemental materials may be provided in an appendix.** All supplemental materials (such as data collection instrument or methodology reports) should be organized in one file with a table of contents or bookmarks. If material pertains to a specific submission form number, that should be indicated. Requested information should be provided in the submission form and required attachments. There is no guarantee that supplemental materials will be reviewed.

[Available at measure-specific web page URL identified in S.1 Attachment:](#)

### Contact Information

**Co.1 Measure Steward (Intellectual Property Owner):** [The Child and Adolescent Health Measurement Initiative](#)

**Co.2 Point of Contact:** [Christina, Bethell, CBethell@cahmi.org, 443-287-5092-](#)

**Co.3 Measure Developer if different from Measure Steward:** [The Child and Adolescent Health Measurement Initiative](#)

**Co.4 Point of Contact:** [Christina, Bethell, CBethell@cahmi.org, 443-287-5092-](#)

### Additional Information

**Ad.1 Workgroup/Expert Panel involved in measure development**

**Provide a list of sponsoring organizations and workgroup/panel members' names and organizations. Describe the members' role in measure development.**

[The Maternal and Child Health Bureau convenes a Technical Expert Panel \(TEP\) comprised of more than a dozen members. Members include other federal agencies, health services researchers, survey methodology experts, consumer organizations and clinical health experts on children's health. The TEP consults in the identification and/or development of items for MCHB to consider for inclusion in the National Survey of Children with Special Health Care Needs, including making recommendations for the scoring and reporting of measures resulting from the national survey.](#)

[Members of the committee are drawn from the public and private sector, including members from national universities and national parenting and family groups, the Child and Adolescent Health Measurement Initiative \(through the MCHB-sponsored Data Resource Center for Child and Adolescent Health\) as well as members from the National Center for Health Statistics, the Centers for Disease Control and Prevention and other federal agencies. There is a range of activity performed by different members of the TEP depending on which measure is being developed, areas of expertise etc. The TEP process usually consists of 1 or 2 in person meetings, 6 or more conference calls, and numerous email exchanges. Subcommittees are formed based on areas of expertise. Because this is a collaborative activity, there is not a single developer of this measure.](#)

**Measure Developer/Steward Updates and Ongoing Maintenance**

**Ad.2 Year the measure was first released:** [2005](#)

**Ad.3 Month and Year of most recent revision:** [02, 2014](#)

**Ad.4 What is your frequency for review/update of this measure?** [Updated every year a new NS-CSHCN is developed](#)

**Ad.5 When is the next scheduled review/update for this measure?** [12, 2017](#)

**Ad.6 Copyright statement:**

**Ad.7 Disclaimers:**

**Ad.8 Additional Information/Comments:**