

<b>CSHCN 1 PERFORMANCE MEASURE</b>	The percent of programs promoting and/ or facilitating family engagement among children and youth with special health care needs.
<b>Goal: Family Engagement</b>	
<b>Level: Grantee</b>	
<b>Domain: CSHCN</b>	
<b>GOAL</b>	To ensure supportive programming for family engagement among children and youth with special health care needs.
<b>MEASURE</b>	The percent of MCHB funded projects promoting and/ or facilitating family engagement among children and youth with special health care needs.
<b>DEFINITION</b>	<p><b>Tier 1:</b> Are you promoting and/ or facilitating family engagement among children and youth with special health care needs in your program?</p> <ul style="list-style-type: none"><li><input type="checkbox"/> Yes</li><li><input type="checkbox"/> No</li></ul> <p><b>Tier 2:</b> Through what processes/ mechanisms are you promoting and/ or facilitating family engagement?</p> <ul style="list-style-type: none"><li><input type="checkbox"/> Technical Assistance</li><li><input type="checkbox"/> Training</li><li><input type="checkbox"/> Product Development</li><li><input type="checkbox"/> Research/ Peer-reviewed publications</li><li><input type="checkbox"/> Outreach/ Information Dissemination/ Education</li><li><input type="checkbox"/> Tracking/ Surveillance</li><li><input type="checkbox"/> Screening/ Assessment</li><li><input type="checkbox"/> Referral/ care coordination</li><li><input type="checkbox"/> Direct Service</li><li><input type="checkbox"/> Quality improvement initiatives</li></ul> <p><b>Tier 3:</b> How many are reached through those activities? <i>(Report in Table 1: Activity Data Collection Form)</i></p> <ul style="list-style-type: none"><li># receiving TA</li><li># receiving training</li><li># products developed</li><li># peer-reviewed publications published</li><li># receiving information and education through outreach</li><li># receiving screening/ assessment</li><li># referred/care coordinated</li><li># received direct service</li><li># participating in quality improvement initiatives</li></ul> <p><b>Tier 4:</b> What are the related outcomes?</p> <ul style="list-style-type: none"><li>% of target population with family and CSHCN leaders with meaningful roles on community/ state/ regional/ national level teams focused on CSHCN systems<ul style="list-style-type: none"><li><b>Numerator:</b> # of Family and CSHCN leaders with meaningful roles on community/state/regional/national level teams focused on CSHCN systems.</li><li><b>Denominator:</b> # of CSHCN in catchment area</li></ul></li><li>% of racial and ethnic family and CSCHN leaders who are trained and serving on community/ state/ regional/ national level teams focused on CSHCN systems.<ul style="list-style-type: none"><li><b>Numerator:</b> #of racial and ethnic family and CSHCN leaders trained and serving on community/state/ regional/ national level teams focused on CSHCN systems.</li><li><b>Denominator:</b> # of CSHCN in catchment area</li></ul></li></ul>

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<b>Goal: Family Engagement</b> <b>Level: Grantee</b> <b>Domain: CSHCN</b>	<p>% of target population with family of CSHCN participating in information exchange forums.</p> <p><b>Numerator:</b> # participating in information exchange forums.</p> <p><b>Denominator:</b> # CSHCN in catchment area</p> <p>% of family and CSCHN leaders trained who report increased knowledge, skill, ability and self-efficacy to serve as leaders on systems-level teams.</p> <p><b>Numerator:</b> # of family and CSHCN leaders trained who report increased knowledge, skill, ability and self-efficacy to serve as leaders on systems-level teams.</p> <p><b>Denominator:</b> # of CSHCN in catchment area.</p> <p><b>Definitions:</b> <u>Family Engagement</u> is defined as “patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system to improve health and health care.” This definition is not intended to negate the various levels or degree to which the interaction between families and professionals can take place. <u>Family and Youth Leaders</u> are family members who have experience navigating through service systems and are knowledgeable and skilled in partnering with professionals to carry out necessary system changes. Family members are not limited to the immediate family within the household. <u>Meaningful [Support] Roles</u> for family members/leaders are above and beyond “feedback” surveys. Families are considered to have a meaningful role in decision making when the partnership involves all elements of shared decision-making which are: collaboration, respect, information sharing, encouragement and consideration of preferences and values, and shared responsibility for outcomes.</p>
<b>BENCHMARK DATA SOURCES</b>	None
<b>GRANTEE DATA SOURCES</b>	Title V National Outcome Measure #17.2
<b>SIGNIFICANCE</b>	Children and youth live within the context of families, who are the ultimate decision-makers and health enablers for their children.

<b>CSHCN 2 PERFORMANCE MEASURE</b>	The percent of programs promoting and/ or facilitating medical home access and use among children and youth with special health care needs.
<b>Goal: Access to and Use of Medical Home</b>	
<b>Level: Grantee</b>	
<b>Domain: CSHCN</b>	
<b>GOAL</b>	To ensure supportive programming medical home access and use among children and youth with special health care needs.
<b>MEASURE</b>	The percent of MCHB-funded projects promoting and/ or facilitating medical home access and use among children and youth with special health care needs.
<b>DEFINITION</b>	<p><b>Tier 1:</b> Are you promoting and/ or facilitating medical home access and use among children and youth with special health care needs?</p> <ul style="list-style-type: none"><li><input type="checkbox"/> Yes</li><li><input type="checkbox"/> No</li></ul> <p><b>Tier 2:</b> Through what processes/ mechanisms are you addressing medical home access and use?</p> <ul style="list-style-type: none"><li><input type="checkbox"/> Technical Assistance</li><li><input type="checkbox"/> Training</li><li><input type="checkbox"/> Product Development</li><li><input type="checkbox"/> Research/ Peer-reviewed publications</li><li><input type="checkbox"/> Outreach/ Information Dissemination/ Education</li><li><input type="checkbox"/> Tracking/ Surveillance</li><li><input type="checkbox"/> Screening/ Assessment</li><li><input type="checkbox"/> Referral/ care coordination</li><li><input type="checkbox"/> Direct Service</li><li><input type="checkbox"/> Quality improvement initiatives</li></ul> <p><b>Tier 3:</b> How many are reached through those activities? <i>(Report in Table 1: Activity Data Collection Form)</i></p> <ul style="list-style-type: none"><li># receiving TA</li><li># receiving training</li><li># products developed</li><li># peer-reviewed publications published</li><li># receiving information and education through outreach</li><li># receiving screening/ assessment</li><li># referred/care coordinated</li><li># received direct service</li><li># participating in quality improvement initiatives</li></ul> <p><b>Tier 4:</b> What are the related outcomes?</p> <p>% of target population that demonstrate a direct linkage to a coordinated medical home community as a direct result of activities conducted by project</p> <p><b>Numerator:</b> Target population with a demonstrated direct linkage to a coordinated medical home.</p> <p><b>Denominator:</b> Target population (as identified in grantee application).</p> <p><b>Definitions:</b> <u>Medical Home</u>: The pediatric medical home can be defined by the AAP as having the following characteristics: the medical care of infants, children, and adolescents ideally should be accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. It should be delivered or directed by well-trained physicians who provide primary care and help to manage and facilitate essentially all aspects of pediatric care.</p>

**CSHCN 2 PERFORMANCE MEASURE**

The percent of programs promoting and/ or facilitating medical home access and use among children and youth with special health care needs.

**Goal: Access to and Use of Medical Home**

**Level: Grantee**

**Domain: CSHCN**

**BENCHMARK DATA SOURCES**

Related to HP2030 MICH-19: Increase the proportion of children and adolescents who receive care in a medical home. (Baseline: 48.6% in 2016-17, Target: 53.6%)

**GRANTEE DATA SOURCES**

Title V National Performance Measure #11

**SIGNIFICANCE**

The American Academy of Pediatrics (AAP) specifies seven qualities essential to medical home care, which include accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally effective. Providing comprehensive and coordinated care to children in a medical home is the standard of pediatric practice. Research indicates that children with a stable and continuous source of health care are more likely to receive appropriate preventive care, are less likely to be hospitalized for preventable conditions, and are more likely to be diagnosed early for chronic or disabling conditions.

<b>CSHCN 3 PERFORMANCE MEASURE</b>	The percent of programs promoting and/or facilitating transition to adult health care for youth with special health care needs.
<b>Goal: Transition Level: Grantee Domain: CSHCN</b>	
<b>GOAL</b>	To ensure supportive programming for transition to adult health care for youth with special health care needs.
<b>MEASURE</b>	The percent of MCHB funded projects promoting and/or facilitating transition to adult health care for youth with special health care needs.
<b>DEFINITION</b>	<p><b>Tier 1:</b> Are you addressing the transitional needs to adult health care for youth with special health care needs in your program?</p> <ul style="list-style-type: none"><li><input type="checkbox"/> Yes</li><li><input type="checkbox"/> No</li></ul> <p><b>Tier 2:</b> Through what activities are you promoting or facilitating the transition to adult health care for youth with special health care needs?</p> <ul style="list-style-type: none"><li><input type="checkbox"/> Technical Assistance</li><li><input type="checkbox"/> Training</li><li><input type="checkbox"/> Product Development</li><li><input type="checkbox"/> Research/ Peer-reviewed publications</li><li><input type="checkbox"/> Outreach/ Information Dissemination/ Education</li><li><input type="checkbox"/> Tracking/ Surveillance</li><li><input type="checkbox"/> Screening/ Assessment</li><li><input type="checkbox"/> Referral/ care coordination</li><li><input type="checkbox"/> Direct Service</li><li><input type="checkbox"/> Quality improvement initiatives</li></ul> <p><b>Tier 3:</b> How many are reached through those activities? <i>(Report in Table 1: Activity Data Collection Form)</i></p> <ul style="list-style-type: none"><li># receiving TA</li><li># receiving training</li><li># products developed</li><li># peer-reviewed publications published</li><li># receiving information and education through outreach</li><li># receiving screening/ readiness assessment</li><li># referred/ care coordinated</li><li># received direct service</li><li># participating in quality improvement initiatives</li></ul> <p><b>Tier 4:</b> What are the related outcomes?</p> <ul style="list-style-type: none"><li>% of grantees promoting an evidence-informed framework and clinical recommendations for transition from pediatric to adult health care. <b>Numerator:</b> Number of Grantees promoting an evidence informed framework. <b>Denominator:</b> Total Number of grantees reporting transition performance measure.</li><li>% of grantees involving both pediatric and adult providers/systems in transition efforts. <b>Numerator:</b> Number of pediatric and adult providers involved in grantee transition efforts. <b>Denominator:</b> Total number of transition practices sponsored by grantee.</li><li>% of grantees initiating or encouraging transition planning early in adolescence.</li></ul>

**CSHCN 3 PERFORMANCE MEASURE**

The percent of programs promoting and/or facilitating transition to adult health care for youth with special health care needs.

**Goal: Transition**  
**Level: Grantee**  
**Domain: CSHCN**

**Numerator:** Number of Grantees promoting transition planning early in adolescence.

**Denominator:** Total number of grantees reporting transition performance measure.

% of grantees linking transition efforts with medical home initiatives.

**Numerator:** Number of Grantees promoting transition as part of routine medical home care.

**Denominator:** Total number of grantees reporting transition performance measure.

% of grantees linking transition efforts with adolescent preventive care efforts.

**Numerator:** Number of grantees promoting transition as part of routine adolescent preventive care.

**Denominator:** Total number of grantees reporting transition performance measure.

**Definitions:** The terms “assessed for readiness” and “deemed ready” used here refer to language utilized by [gottransition.org](http://gottransition.org).

**Health care transition:** is the process of changing from a pediatric to an adult model of health care. The goal of transition is to optimize health and assist youth in reaching their full potential. To achieve this goal requires an organized transition process to support youth in acquiring independent health care skills, preparing for an adult model of care, and transferring to new providers without disruption in care.

**Transition Readiness:** Assessing youth’s transition readiness and self-care skills is the third element in these health care transition quality recommendations. Use of a standardized transition assessment tool is helpful in engaging youth and families in setting health priorities; addressing self-care needs to prepare them for an adult approach to care at age 18, and navigating the adult health care system, including health insurance. Providers can use the results to jointly develop a plan of care with youth and families. Transition readiness assessment should begin at age 14 and continue through adolescence and young adulthood, as needed.

**BENCHMARK DATA SOURCES**

Related to HP2030 AH-02: Increase the proportion of adolescents who speak privately with a physician or other health care provider during a preventive medical visit. (Baseline: 38.4% in 2016-17, Target: 43.3%). Related to HP2030 AH-R01: Increase the proportion of adolescents (aged 12 to 17 years) with and without special health care needs who receive services to support their transition to adult health care. (Research)

**GRANTEE DATA SOURCES**

Title V National Performance Measure #12.

**SIGNIFICANCE**

Over 90 percent of children with special health care needs now live to adulthood, but are less likely than their non-disabled peers to complete high school, attend college, or be employed. Health and health care are cited as two of the major barriers to making successful transitions. The transition of youth to adulthood,

**CSHCN 3 PERFORMANCE MEASURE**

The percent of programs promoting and/or facilitating transition to adult health care for youth with special health care needs.

**Goal: Transition**

**Level: Grantee**

**Domain: CSHCN**

including moving from a child to adult healthcare, is a national priority as evidenced by the 2011 clinical report and algorithm developed jointly by the AAP, American Academy of Family Physicians and American College of Physicians to improve healthcare transitions for all youth and families.<sup>1</sup>

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<sup>1</sup> White PH, Cooley WC. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2018; 142 (5): e20182587. <https://doi.org/10.1542/peds.2018-2587>