CSHCN 1 Performance Measure **Goal: Family Engagement** **Level: Grantee** **Domain: CSHCN**	The percent of programs promoting and/ or facilitating family engagement among children and youth with special health care needs.
GOAL	To ensure supportive programming for family engagement among children and youth with special health care needs.
MEASURE	The percent of MCHB funded projects promoting and/ or facilitating family engagement among children and youth with special health care needs.
DEFINITION	**Tier 1**: Tier 1: Are you promoting and/ or facilitating family engagement among children and youth with special health care needs in your program? ☐ Yes ☐ No **Tier 2**: Through what processes/ mechanisms are you promoting and/ or facilitating family engagement? ☐ Technical Assistance ☐ Training ☐ Product Development ☐ Research/ Peer-reviewed publications ☐ Outreach/ Information Dissemination/ Education ☐ Tracking/ Surveillance ☐ Screening/ Assessment ☐ Referral/ care coordination ☐ Direct Service ☐ Quality improvement initiatives **Tier 3**: How many are reached through those activities? *(Report in Table 1: Activity Data Collection Form)* # receiving TA # receiving training # products developed # peer-reviewed publications published # receiving information and education through outreach # receiving screening/ assessment # referred/care coordinated # received direct service # participating in quality improvement initiatives *(continued on next page →)*

CSHCN 1 Performance Measure **Goal: Family Engagement** **Level: Grantee** **Domain: CSHCN**	The percent of programs promoting and/ or facilitating family engagement among children and youth with special health care needs.

DEFINITION (continued)

Tier 4: What are the related outcomes?

% of target population with family and CSHCN leaders with meaningful roles on community/ state/ regional/ national level teams focused on CSHCN systems

Numerator: # of Family and CSHCN leaders with meaningful roles on community/state/regional/national level teams focused on CSHCN systems

Denominator: # of CSHCN in catchment area

% of racial and ethnic family and CSCHN leaders who are trained and serving on community/ state/ regional/ national level teams focused on CSHCN systems

Numerator: #of racial and ethnic family and CSHCN leaders trained and serving on community/state/ regional/ national level teams focused on CSHCN systems

Denominator: # of CSHCN in catchment area

% of target population with family of CSHCN participating in information exchange forums

Numerator: # participating in information exchange forums

Denominator: # CSHCN in catchment area

% of family and CSCHN leaders trained who report increased knowledge, skill, ability and self-efficacy to serve as leaders on systems-level teams

Numerator: # of family and CSHCN leaders trained who report increased knowledge, skill, ability and self-efficacy to serve as leaders on systems-level teams

Denominator: # of CSHCN in catchment area

Definitions:

Family Engagement 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.

Family and Youth Leaders 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.

Meaningful [Support] Roles 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.

BENCHMARK DATA SOURCES

Related to Healthy People 2020 Family Planning Objectives

GRANTEE DATA SOURCES

Title V National Performance Measure #2

CSHCN 1 Performance Measure **Goal: Family Engagement** **Level: Grantee** **Domain: CSHCN**	The percent of programs promoting and/ or facilitating family engagement among children and youth with special health care needs.
SIGNIFICANCE	In recent years, policy makers and program administrators have emphasized the central role of family engagement in policy-making activities. In accordance with this philosophy, MCHB is facilitating such partnerships at the local, state and national levels. While there has been a significant increase in the level and types of family engagement, there is still a need to share strategies and mechanisms to recruit, train, monitor, and evaluate family engagement as a key component for CSHCN.

CSHCN 2 Performance Measure **Goal: Access to and Use of Medical Home** **Level: Grantee** **Domain: CSHCN**	The percent of programs promoting and/ or facilitating medical home access and use among children and youth with special health care needs.
GOAL	To ensure supportive programming medical home access and use among children and youth with special health care needs.
MEASURE	The percent of MCHB-funded projects promoting and/ or facilitating medical home access and use among children and youth with special health care needs.
DEFINITION	**Tier 1**: Are you promoting and/ or facilitating medical home access and use among children and youth with special health care needs? ☐ Yes ☐ No **Tier 2**: Through what processes/ mechanisms are you addressing medical home access and use? ☐ Technical Assistance ☐ Training ☐ Product Development ☐ Research/ Peer-reviewed publications ☐ Outreach/ Information Dissemination/ Education ☐ Tracking/ Surveillance ☐ Screening/ Assessment ☐ Referral/ care coordination ☐ Direct Service ☐ Quality improvement initiatives **Tier 3**: How many are reached through those activities? (*Report in Table 1: Activity Data Collection Form*) # receiving TA # receiving training # products developed # peer-reviewed publications published # receiving information and education through outreach # receiving screening/ assessment # referred/care coordinated # received direct service # participating in quality improvement initiatives **Tier 4**: What are the related outcomes? % of target population that demonstrate a direct linkage to a coordinated medical home community as a direct result of activities conducted by project **Numerator:** Target population with a demonstrated direct linkage to a coordinated medical home. **Denominator:** Target population (as identified in grantee application) **Definitions:** Medical Home: 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.
BENCHMARK DATA SOURCES	Objective # MICH-30.2: Increase the proportion of children with special health care needs who have access to a medical home

CSHCN 2 Performance Measure **Goal: Access to and Use of Medical Home** **Level: Grantee** **Domain: CSHCN**	The percent of programs promoting and/ or facilitating medical home access and use among children and youth with special health care needs.
	(Baseline: 47.1% in 2005-2006, Target: 51.8%)
GRANTEE DATA SOURCES	NSCH Indicator 4.8, NSCH Indicator 4.9d, Title V National Performance Measure #3
SIGNIFICANCE	Medical homes are a cultivated partnership between patients, family, and primary care providers in coordination with support from the community. These models ensure that care must be accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective.

CSHCN 3 Performance Measure **Goal: Transition** **Level: Grantee** **Domain: CSHCN**	The percent of programs promoting and/or facilitating transition to adult health care for youth with special health care needs.
GOAL	To ensure supportive programming for transition to adult health care for youth with special health care needs.
MEASURE	The percent of MCHB funded projects promoting and/or facilitating transition to adult health care for youth with special health care needs.
DEFINITION	**Tier 1**: Are you addressing the transitional needs to adult health care for youth with special health care needs in your program? ☐ Yes ☐ No **Tier 2**: Through what activities are you promoting or facilitating the transition to adult health care for youth with special health care needs? ☐ Technical Assistance ☐ Training ☐ Product Development ☐ Research/ Peer-reviewed publications ☐ Outreach/ Information Dissemination/ Education ☐ Tracking/ Surveillance ☐ Screening/ Assessment ☐ Referral/ care coordination ☐ Direct Service ☐ Quality improvement initiatives **Tier 3**: How many are reached through those activities? *(Report in Table 1: Activity Data Collection Form)* # receiving TA # receiving training # products developed # peer-reviewed publications published # receiving information and education through outreach # receiving screening/ readiness assessment # referred/ care coordinated # received direct service # participating in quality improvement initiatives *(continued on next page →)*

CSHCN 3 Performance Measure **Goal: Transition** **Level: Grantee** **Domain: CSHCN**	The percent of programs promoting and/or facilitating transition to adult health care for youth with special health care needs.
DEFINITION (Continued)	**Tier 4**: What are the related outcomes? % of grantees promoting an evidence-informed framework and clinical recommendations for transition from pediatric to adult health care. **Numerator:** Number of Grantees promoting an evidence informed framework **Denominator:** Total Number of grantees reporting transition performance measure % of grantees involving both pediatric and adult providers/systems in transition efforts **Numerator:** Number of pediatric and adult providers involved in grantee transition efforts **Denominator:** Total number of transition practices sponsored by grantee % of grantees initiating or encouraging transition planning early in adolescence **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. <u>Health care transition:</u> 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. <u>Transition Readiness:</u> 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	NA

CSHCN 3 Performance Measure **Goal: Transition** **Level: Grantee** **Domain: CSHCN**	The percent of programs promoting and/or facilitating transition to adult health care for youth with special health care needs.
GRANTEE DATA SOURCES	Title V National Performance Measure #6 and #12, NS-CSHCN Survey Outcome #6
SIGNIFICANCE	Transitioning of children to adolescent services to adult services is important to ensure that growth and development is adequately and accurately screened throughout all stages. These stages of life represent a time of rapid development and it is important to make sure changes are documented and children and receiving appropriate treatment, preventive services, and screenings.