



ChampionsInC Community-based Assessment Tool for Title V CSHCN Leaders:

Examining State Capacity for Achieving a Community-Based Service System for Children and Youth with Special Health Care Needs

Overview of Title V CSHCN Programs

Title V funding for children with special health care needs has evolved over the past fifty years, moving from: funding “Crippled Children’s Programs”; to addressing social, emotional, and physical needs of children via a community-based systems of services. Title V of the Social Security Act now provides guidance and funds to States and territories to:

- provide and promote ***family-centered, community-based, coordinated care*** for children and youth with special health care needs (CYSHCN)
- facilitate the development of ***community-based systems*** of services
- support ***core public health functions*** such as resource development, capacity building, public information, technical assistance to communities, and provider training
- build ***community capacity*** to deliver care coordination, and coalitions
- Fill gaps in need for direct health care services for children and families

Assessing your state’s capacity

Under the Omnibus Budget Reconciliation Act of 1989 (OBRA) and Healthy People 2010, states are instructed to achieve a community-based system of services and supports for children and youth with special health care needs and their families. The six performance measures for CYSHCN articulated in the Title V Block Grant provides structure for this assessment:

PM 1: Timely follow up to definitive diagnosis and clinical management for condition(s) mandated by their State-sponsored newborn screening programs.

PM 2: Families partner in decision making at all levels and are satisfied with the services they receive.

PM 3: Children receive coordinated, ongoing, comprehensive care within a medical home.

PM 4: Families have adequate private and/or public insurance to pay for the services they need.

PM 5: Families report the community-based service systems are organized so they can use them easily.

PM 6: Youth with special health care needs who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

Role of this Community-Based Assessment

This ChampionsInC Community-Based Assessment Tool is designed to assist CYSHCN leaders in the needs assessment process, with focus on the ***state's capacity in implementing community-based service systems***. Specifically, the needs assessment helps with identifying:

1. Who are the needed stakeholders, representing families, youth, community providers, and other important players in the service system at the state level?
2. What state level policies and practices should be in place to achieve these outcomes?
3. What policies and practices should be in place across communities in your state?
4. What are some data sources or ways to measure achievements for children, youth, and families?

Important elements of such a system at the state and community level have been identified in this tool, though these elements are not exhaustive. Rather, they reflect basic components to get started -- additional partners and elements may be needed to reflect the characteristics of individual states and communities. Resources for obtaining training and technical assistance related to the CYSHCN performance outcomes are provided at the end of this document.

Instructions for Completing this assessment

This assessment is best completed by a team of state stakeholders, in partnership with community and family leaders. Together:

1. Put a check in the box pertaining to the level of development for each component.
2. After reviewing all components, go back to the beginning and identify your priorities.

PM 1: EARLY AND CONTINUOUS SCREENING

Who do you need as partners at a state level? Rate the level of engagement of the following key partners:

	Strong engagement	Moderate engagement	Weak engagement	No participation	Priority?
a. CSHCN and MCH administration	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. EHDI, newborn dried bloodspot screening programs, public health laboratories	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Part C EI /other EC programs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Mental health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Family and youth leaders reflective of your state's diversity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. March of Dimes and other patient/family support organizations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Pediatric and obstetric health professionals and their organizations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Third party payers and employers, hospitals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Relevant agencies such as CMS (EPSDT), Education (Head Start, daycare), Housing (lead), Agriculture (WIC, nutrition), etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. LEND programs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

What state policies and practices are needed?

	Well established/sustained	Implementation initiated	Plan in development	Not developed	Priority?
a. Integrated information systems for surveillance, follow up, service coordination, and quality improvement. Systems should have privacy and confidentiality protection in place.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Coordinated referral process to facilitate diagnostic testing and patient management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Promotion of Bright Futures Guidelines and other relevant guidelines and standards and require their use in grant funding and contracts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Medical home training in comprehensive screening, including mental health, ASD, OAE (hearing), development	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Well established/ sustained	Implementation initiated	Plan in development	Not developed	Priority?
e. Availability of screening information in languages spoken by majority of state residents and that's easily understood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Identification of best screening practices and tools	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Promote and support the use of health information technology, such as telemedicine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Provide funding to encourage coordination of screening activities at local, regional, and state levels	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Increase compensation rates for screening activities in the medical homes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. State external advisory committee to promote coordination and oversight	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Collect and analyze data for continuous monitoring, evaluation, and planning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. Promote awareness of the need and benefits of early and continuous screening	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. Participate in the MCHB funded Regional Newborn Screening and Genetic Services Collaborative activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How can states support community policies and practices?

	Well established/ sustained	Implementation initiated	Plan in development	Not developed	Priority?
a. Local interagency screening clinics/other systems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Local use of integrated information systems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Coordinated referral process employed by local providers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Use of cultural brokers in public awareness efforts to promote screening	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Community grants to facilitate coordination of screening activities, data collection and reporting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Provide training for various screening activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

What are some ways of measuring needs and outcomes for children and families?

	Data available & shared with communities for planning	Data available & used for state planning	Data available & used for reporting purposes	Data not available	Priority
a. National Survey of Children’s Health 2007 (CSHCN receiving preventive medical and dental care visits)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. National Survey of CSHCN 2005/2006 (CSHCN receiving both preventive medical/dental care during the past 12 months)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Pregnancy Risk Assessment Survey	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. State newborn dried bloodspot screening and EHDI data bases	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. National Newborn Screening Information System	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. MCHB’s Discretionary Grant Information System (DGIS) performance measure 23	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

PM 2: CYSHCN WHOSE FAMILIES ARE PARTNERS AT ALL LEVELS OF DECISION MAKING

Who do you need as partners at a state level?

	Strong engagement	Moderate engagement	Weak engagement	No participation	Priority?
a. Family leadership/advocacy groups (e.g., Family Voices, Parent Training and Information Centers)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Family members representing their individual needs, with persons who reflect of the diverse populations in the state	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. State CSCHN administration	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. State CYSCHN decision-making boards/councils	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Medical home providers and medical home family representatives	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

What state policies and practices are needed?

	Well established/ sustained	Implementation initiated	Plan in development	Not developed	Priority?
a. Family leadership training/mentoring system in place for families and financially supported	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Families are leaders in lobbying and social marketing for CYSHCN system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Family leaders, representing the diversity of the state	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Family representative has a CSHCN staff position or are contracted employee	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Family leaders are active members of state policy and advisory boards	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How can states support community policies and practices?

	Well established/ sustained	Implementation initiated	Plan in development	Not developed	Priority?
a. Family leader positions exist in communities across state	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	
b. Family leaders are members of local boards, such as local interagency councils	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	
c. Families are supported financially for their involvement	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	
d. Family leadership training/networking are implemented in communities	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	

What are some ways of assessing needs and outcomes for children, youth and families?

	Data available & shared with communities for planning	Data available & used with state planning	Data available & used for reporting purposes	Data not available	Priority?
a. Block Grant reporting rating scale---Form 13	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. National Survey of Children’s Health 2007 (parent feels like partner in child’s care)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Family to Family Health Information Center data re: outcomes of training provided	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Parent Training and Information Center data re: outcomes of training provided	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Center for Medical Home Improvement: Family survey	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. National Center for Cultural Competence Self-Assessment Survey	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. MCHB’s Discretionary Grant Information System (DGIS) performance measures 6 , 7, and 64	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

PM 3: CYSHCN RECEIVE COORDINATED, ONGOING, COMPREHENSIVE CARE WITHIN THE MEDICAL HOME

Who do you need as partners?

	Strong engagement	Moderate engagement	Weak engagement	No participation	Priority?
a. Physicians: AAP chapter leaders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Primary care providers (i.e., Pediatricians, Family Practice)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Specialists and subspecialists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. CSHCN program administration	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strong engagement	Moderate engagement	Weak engagement	No participation	Priority?
e. Medical schools and residency training programs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Family and youth leaders who reflect the diversity in your state	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Education (including Head Start), Medicaid, private insurers, employers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Nursing and allied health professionals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. State epidemiologists and health information technology staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Community service providers and leaders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

What state policies and practices are needed?

	Well established/sustained	Implementation initiated	Plan in development	Not developed	Priority?
a. Statewide Medical home training/TA for pediatric practices, families, and adult providers to support transition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Medical home part of medical school/residency training.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Increased reimbursement for Med. Home via Medicaid, other private insurers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Translation/interpretation supports for medical homes to serve culturally and linguistically diverse populations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Promote and support health information technology initiatives that connect public health to clinical practices and/or promote the use of electronic health records and personal health records, telemedicine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. state-wide medical home demonstration projects and pilots	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Disseminate best practices and tools for medical home implementation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Public awareness activities are conducted throughout the state	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Health literacy is promoted with	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Well established/sustained	Implementation initiated	Plan in development	Not developed	Priority?
j. specific outreach to the medically underserved	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Represent the medical homes in state emergency contingency/diaster planning activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How can states support community policies and practices?

	Well established/sustained	Implementation initiated	Plan in development	Not developed	Priority?
a. Practices are involved in medical home training and/or serve as mentors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Medical homes are ID'd and included in all CSHCN service plans	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Medical homes are represented on local councils/coalitions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Medical homes partner with other entities to ensure coordinated care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Medical homes are included in IEPs/IFSPs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Translation/interpretation supports for medical homes to serve diverse families	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Provide resources to community-based practices for care coordination	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Assist in compiling a directory of community services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

What are some ways of measuring needs and outcomes for children and families?

	Data available & shared with communities for planning	Data available & used with state planning	Data available & used for reporting purposes	Data not available	Priority?
a. National Survey of CSHCN 2007 associated indicators for medical home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. National Survey of Children’s Health associated indicators for medical home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Center for Medical Home Improvement: Physician and family surveys	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. F2FHIC data regarding medical home needs/challenges	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. MCHB’s Discretionary Grant Information System (DGIS) performance measure #19 and 64	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

PM 4: ADEQUATE INSURANCE/FINANCING

Who do you need as partners?

	Strong engagement	Moderate engagement	Weak engagement	No participation	Priority?
a. CSHCN program administrators	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. CMS/Medicaid, SCHIP	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Private insurers/Managed Care providers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Family and youth leaders who represent the diversity in your state	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Primary care and specialty physicians, mental health providers, ancillary care providers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

What state policies and practices are needed?

	Well established/ sustained	Implementation initiated	Plan in development	Not developed	Priority?
a. There is a F2FHIC/other statewide program for assisting families, providers with information, resources about health care financing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. State CSHCN program & families are represented on insurance boards, Medicaid councils	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. The State has expanded eligibility for Medicaid, SCHIP	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. State initiatives to support universal, comprehensive coverage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Strong public awareness and simplified application procedures for Medicaid/SCHIP (e.g., online application process)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. State has streamlined application process for Medicaid/SCHIP applications (e.g., utahclicks.org)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Training in benefits management is provided to care coordinators	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How can states support community policies and practices?

	Well established/ sustained	Implementation initiated	Plan in development	Not developed	Priority?
a. Strong public awareness initiatives to recruit eligible families for Medicaid/SCHIP, esp. diverse families	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Training for providers to support families in obtaining insurance coverage- insurance “navigators”	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Community-based /school based health centers to support uninsured/underinsured	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Blended funding available to support uninsured/underinsured	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

What are some ways of assessing needs and outcomes of children and families?

	Data available & shared with communities for planning	Data available and used with state planning	Data available & used for reporting purposes	Data not available	Priority?
a. National Survey of CSHCN 2005/2006, indicators re: adequate insurance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. National Survey of Children’s Health 2007, indicators re: health insurance coverage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. F2FHIC data pertaining to family requests for support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Child and Adolescent Health Program (CAHPS), child survey	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

PM 5: COMMUNITY-BASED SERVICES ARE ORGANIZED AND FAMILIES ARE SATISFIED

Who do you need as partners at a state level?

	Strong engagement	Moderate engagement	Weak engagement	No participation	Priority?
a. CSHCN administrators	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Public health administrators and providers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. State interagency councils/advisory boards	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Medical home representatives	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Family and Youth leaders who represent the diversity of your state	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Faith-based organizations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Nonprofits, charities (e.g., Shriners)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

What state policies and practices are needed?

	Well established/ sustained	Implementation initiated	Plan in development	Not developed	Priority?
a. CSHCN Statewide regional/local offices/infrastructure is in place	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. CSHCN care coordination is available throughout the state	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Streamlined/common application process for multiple services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Contracts w/community based providers vs. centralized clinics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. State funding available to support communities (e.g., "mini-grants")	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. State agencies create a common application process	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How can states support community policies and practices?

	Well established/ sustained	Implementation initiated	Plan in development	Not developed	Priority?
a. Regional/local CSHCN offices are part of statewide infrastructure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Funds are provided for regional/local level CSHCN care coordinators	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Community-level councils/coalitions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Community-based versus centralized health care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Cultural brokers to ensure needs of all families are met	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Common application process to facilitate access to services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Single Interagency care plans	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

What are some ways of assessing needs and outcomes of children and families?

	Data available & shared with communities for planning	Data available & used with state planning	Data available & used for reporting purposes	Data not available	Priority?
a. National Survey of CSHCN 2005/2006, indicators re: outcome 5: Families of CYSHCN report that services are organized so they can use them easily; Families are satisfied with the services they receive (National Survey of CSHCN associated indicators); Families report that they can access all needed services in a timely manner (National Survey of CSHCN associated indicators); Families report that they have a care coordinator and reported # of hours families coordinate care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. National Survey of Children’s Health 2007, indicators re: unmet needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. National Center for Cultural Competence Self Assessment Survey	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Child and Adolescent Health Program (CAHPS), child survey	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Family Voices data	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. F2FHIC data Champions for Inclusive Communities community-level mapping and survey strategies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. MCHB’s Discretionary Grant Information System (DGIS) performance measure #37	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	

PM 6: TRANSITION TO ADULT LIFE

Who do you need as partners?

	Strong engagement	Moderate engagement	Weak engagement	No participation	Priority?
a. Youth leadership organizations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Family leadership organizations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. State Title V CSHCN administrators	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Public and private insurance representatives	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strong engagement	Moderate engagement	Weak engagement	No participation	Priority?
e. Pediatricians and adult medical providers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Secondary and post-secondary educators	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Representatives from Office of Rehabilitation Services and other government funded economic support services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Private employment representatives	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Assisted living/personal assistant representatives	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Major businesses that can offer employment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Public Transportation administrators	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

What state policies and practices are needed?

	Well established/sustained	Implementation initiated	Plan in development	Not developed	Priority?
a. Youth representatives are financially supported	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Youth advisory council created	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Youth leaders present on interagency councils	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Medical home training to support transition to adult care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Youth leadership training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Youth website for resources, peer-to-peer interaction	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. State legislation to support insurance coverage for adults with CSHCN	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Health insurance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Systems and supports in place that support employment for youth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Home and community based services are adequately funded	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Health goals are integrated into education and transition plans –increased awareness of health impacting educational/vocational goals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How can states support community policies and practices?

	Well established/ sustained	Implementation initiated	Plan in development	Not developed	Priority?
a. Pediatricians and adult providers receive training to support transition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Youth reps on local councils	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Youth reps in local councils/coalitions and financially supported	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Transportation options are available in communities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Community-based youth groups financially supported	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Comprehensive school transition plans that include health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Supporting interagency councils targeting transition issues for youth/young adult	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

What are some ways of assessing needs of youth and families?

	Data available & shared with communities for planning	Data available & used with state planning	Data available & used for reporting purposes	Data not available	Priority?
a. National Survey of CSHCN 2005/2006, indicators re: transition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. National Survey of Children’s Health 2007 (re: middle childhood and adolescence)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Families of YSCHN report supports for transition to adulthood (National Survey of CSHCN associated indicators)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Family Voices data	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. F2FHIC data	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. National Health Interview Survey – Disabilities survey	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. BRFSS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Education data regarding transition planning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Office of Rehabilitative Services Data	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Resources for Assisting States in their Needs Assessment and Planning Efforts

The Maternal and Child Health Bureau's Division of Services for Children with Special Health Needs funds national centers whose mission is to serve as a resource in your efforts to achieve the six outcomes for CYSHCN and their families. The centers below can assist you in building partnerships, developing and implementing plans, as well as measuring your efforts to achieve these outcomes. These major centers are described below:

Family Voices National Center for Family Professional Partnerships (NCFPP)

The NCFPP provides leadership on implementing the core component of a system of care for children and youth with special health care needs (CYSHCN) working to increase the capacity of families to partner in decision making at all levels. The NCFPP works nationally with F2FHICs, the FV network, other family leaders and their professional partners in implementing this core component. <http://www.familyvoices.org>

National Center for Cultural Competence (NCCC)

The NCCC provides national leadership and contributes to the body of knowledge on cultural and linguistic competency within systems and organizations. Major emphasis is placed on translating evidence into policy and practice for programs and personnel concerned with health and mental health care delivery, administration, education and advocacy.

<http://www11.georgetown.edu/research/gucchd/nccc>

Healthy & Ready to Work National Resource Center (HRTW)

The Center works with State Title V CSHN programs and their partners to improve and enhance health care transition for CYSHCN. The Center provides resources, information and technical assistance addressing the transition to adult systems and services including strategies to maintain health insurance and increasing the involvement of youth in health care decisions and policymaking. The website includes tools and resources for providers, families and youth. www.hrtw.org

The National Center for Medical Home Initiatives for Children with Special Needs

The National Center of Medical Home Initiatives for Children with Special Needs provides support to physicians, families, and other medical and non-medical providers who care for children with special needs so that they have access to a medical home. <http://www.medicalhomeinfo.org/index.html>

The Catalyst Center

A national center dedicated to improving health care insurance and financing for children and youth with special health care needs (CYSHCN). <http://www.hdwg.org/catalyst>

Champions for Inclusive Communities (ChampionsInC)

A leadership and resource center designed to support states and communities in organizing services so families of children and youth with special health care needs (CYSHCN) can use them easily and families are satisfied. <http://www.championsinc.org>

National Center for Hearing Assessment and Management (NCHAM)

This National Resource Center (NRC) assists state agencies and other federal and non-federal partners in the development and operation of sustainable statewide Early Hearing Detection and Intervention (EHDI) systems. <http://www.infanthearing.org>

CAHMI Data Resource Center

Part of the Child & Adolescent Health Measurement Initiative. Provides leadership and resources for measuring and communicating information about the quality of healthcare for young children (0-3), teens (12-21), and children with chronic conditions. <http://cahmi.org/pages/Sections.aspx?section=14>