

## THE MEDICAL HOME INDEX: Measuring the Organization and Delivery of Primary Care for Children with Special Health Care Needs

This tool defines, describes, and quantifies activities related to the organization and delivery of primary care for *Children with Special Health Care Needs (CSHCN)*. You will be asked to rank the level of your practice in six domains: organizational capacity, chronic condition management, care coordination, community outreach, data management and quality improvement/change. Most practices may not function at many of the higher levels (Levels 3 and 4). However, these levels do represent care matched to the kinds of services and supports that families of *CSHCN* report that they need. A frank assessment of your current practice is desirable; this will best define practice and help to identify the supports needed by pediatric practices to better serve *CSHCN* in their communities. Families will complete a companion instrument commenting on their experiences with your practice.

Name: \_\_\_\_\_ Title/Position/Role: \_\_\_\_\_

Address/Phone/e-mail/fax: \_\_\_\_\_

Describe Your Practice Type/Model: \_\_\_\_\_ Number of Providers: MDs \_\_\_\_\_ ARNPs \_\_\_\_\_ PA's \_\_\_\_\_ Other \_\_\_\_\_

Is there a care coordinator working at your practice who supports *CSHCN*/families?  Yes  No {Use other side of sheet to explain.}

What is the estimated number of children that your practice cares for? \_\_\_\_\_ What is your patient panel size? \_\_\_\_\_

Can you estimate the percentage (Total should = 100%) of children you care for who have:

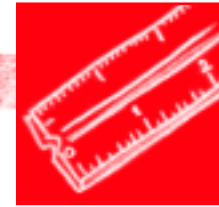
- |  |   |                         |
|--|---|-------------------------|
| 1) _____% <b>Public insurance only (Medicaid/CHIP)</b> | 2) _____% <b>Private &amp; Medicaid</b> |                         |
| 3) _____% <b>Self/No pay</b>                           | 4) _____% <b>Private insurance only</b> | 5) _____% <b>Other?</b> |

How familiar/knowledgeable are you about the concept of a medical home as defined by the American Academy of Pediatrics?

- |   |   |
|---|---|
| 1) <input type="checkbox"/> No knowledge of the concept                         | 2) <input type="checkbox"/> Some knowledge/not applied                          |
| 3) <input type="checkbox"/> Knowledgeable/concept sometimes applied in practice | 4) <input type="checkbox"/> Knowledgeable/concept regularly applied in practice |

How familiar/knowledgeable are you with the elements of family-centered care as defined by the Institute on Family Centered Care?

- |  |  |
|--|--|
| 1) <input type="checkbox"/> No knowledge of the concepts                         | 2) <input type="checkbox"/> Some knowledge/not applied                           |
| 3) <input type="checkbox"/> Knowledgeable/concepts sometimes applied in practice | 4) <input type="checkbox"/> Knowledgeable/concepts regularly applied in practice |



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### DEFINITIONS OF CORE CONCEPTS \*

#### *Children with Special Health Care Needs (CSHCN):*

Children with special health care needs are defined by the *US Maternal and Child Health Bureau* as those who have, or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children generally (USDHHS, MCHB, 1997).

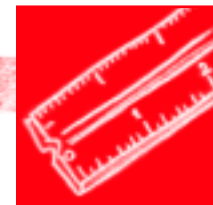
#### *Medical Home* according to the American Academy of Pediatrics (AAP):

A community-based primary care “medical home” is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent.

#### *Elements of Family-Centered Care* (Institute on Family Centered Care, Bethesda, Maryland):

- 1) Recognizing that the family is the constant in a child's life, the service systems and personnel within those systems fluctuate
- 2) Facilitating family-professional collaboration at all levels of health care
- 3) Honoring the racial, ethnic, cultural and socioeconomic diversity of families
- 4) Recognizing family strengths and individuality and respecting different methods of coping
- 5) Sharing with parents, on a continuing basis and in a supportive manner, complete and unbiased information
- 6) Encouraging and facilitating family-to-family support and networking
- 7) Understanding and incorporating the developmental needs of infants, children, and adolescents & families into health systems
- 8) Implementing comprehensive policies and programs that provide emotional and financial support to meet the needs of families
- 9) Designing accessible health care systems that are flexible, culturally competent, and responsive to family-identified needs

\* Words referenced here will be in italics throughout the document.



## THE MEDICAL HOME INDEX: Measuring the Organization and Delivery of Primary Care for Children with Special Health Care Needs

### GLOSSARY OF TERMS\*

#### *Care Coordination Activities:*

Care and services performed in partnership with the family and providers by health professionals to:

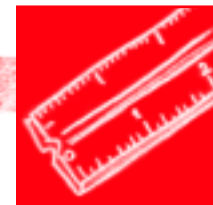
- 1) Establish family-centered community-based “**Medical Homes**” for *CSHCN* and their families.
  - Make assessments and monitor child and family needs
  - Participate in parent/professional practice improvement activities
- 2) Facilitate timely access to the *Primary Care Provider (PCP)*, services and resources
  - Offer supportive services including counseling, education and listening
  - Facilitate communication among PCP, family and others
- 3) Build bridges among families and health, education and social services; promotes continuity of care
  - Develop, monitor, update and follow-up with care planning and care plans
  - Organize wrap around teams with families; support meeting recommendations and follow-up
- 4) Supply/provide access to referrals, information and education for families across systems.
  - Coordinate inter-organizationally
  - Advocate with and for the family (e.g. to school, daycare, or health care settings)
- 5) Maximize effective, efficient, and innovative use of existing resources
  - Find, coordinate and promote effective and efficient use of current resources
  - Monitor outcomes for child, family and practice

#### *Chronic Condition Management (CCM):*

CCM acknowledges that children and their families may require more than the usual well child, preventive care, and acute illness interventions. CCM involves explicit changes in the roles of providers and office staff aimed at improving:

- 1) Access to needed services
- 2) Communication with specialists, schools, and other resources, and
- 3) Outcomes for children and families.

**\*Words referenced here will be in italics throughout the document.**



## THE MEDICAL HOME INDEX: Measuring the Organization and Delivery of Primary Care for Children with Special Health Care Needs

### GLOSSARY OF TERMS\* (continued)

#### *Quality:*

Quality is best determined or judged by those who need or who use the services being offered. Quality in the medical home is best achieved when one learns what children with special health care needs and their families require for care and what they need for support. Health care teams in partnership with families then work together in ways which enhance the capacity of the family and the practice to meet these needs. Responsive care is designed in ways which incorporate family needs and suggestions. Those making practice improvements must hold a commitment to doing what needs to be done and agree to accomplish these goals in essential partnerships with families.

#### *Office Policies*

Definite courses of action adopted for expediency; “the way we do things”; these are clearly articulated to and understood by all who work in the office environment.

#### *Practice:*

The place, providers, and staff where the PCP offers pediatric care

#### *Primary Care Provider - (PCP):*

Physician or pediatric nurse practitioner who is considered the main provider of health care for the child

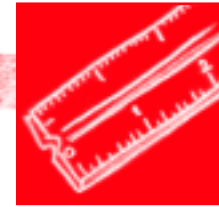
#### *United States Maternal and Child Health Bureau - (USMCHB):*

A division of Health Resources Services Administration

**Requires both MD and key non-MD staff person’s perspective** – you will see this declaration before select themes; the project has found that these questions require the input of both MD and non MD staff to best capture practice activity.

**\*Words referenced here will be in italics throughout the document**

*Medical Home Index instructions begin on the next page...*



## THE MEDICAL HOME INDEX: Measuring the Organization and Delivery of Primary Care for Children with Special Health Care Needs

### INSTRUCTIONS:

The Medical Home Index has six domains that include:

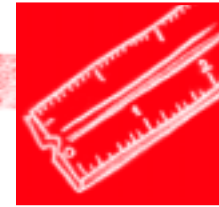
Organizational Capacity	Chronic Condition Management	Care Coordination
Community Outreach	Data Management, and	Quality Improvement

Each domain has anywhere from 2-7 themes, these themes are represented with a progression of care and are expressed as a continuum from Level 1-Level 4. For each theme please do the following:

- First:** Read each theme across its progressive continuum from Levels 1 to Level 4. Then,
- Second:** Select the LEVEL (1, 2, 3 or 4) which best describes how your *practice* currently provides care for *CSHCN*.
- Third:** When you have selected the Level, then indicate whether *practice* performance within that level is: “PARTIAL” (some activity within level) or “COMPLETE” (all activity within that level).

For the example below, “Domain 1: Organizational Capacity, Theme 1.1 “The Mission...” the score for the *practice* is: “Level 3”, “PARTIAL”.

Domain 1: Organizational Capacity: For <span style="border: 2px solid black; padding: 2px;">EXAMPLE</span> and Their Families				
THEME:	<i>Level 1</i>	<i>Level 2</i>	<i>Level 3</i>	<i>Level 4</i>
<b>#1.1 The Mission of the Practice</b>	<p><i>Primary care providers (PCPs) at the practice have individual ways of delivering care to children with special health care needs CSHCN; their own education, experience and interests drive care quality.</i></p> <p style="text-align: center;"><input type="checkbox"/> PARTIAL   <input type="checkbox"/> COMPLETE</p>	<p>Approaches to the care of CSHCN at the practice are child rather than <i>family-centered</i>; office needs drive the implementation of care (e.g. the process of carrying out care).</p> <p style="text-align: center;"><input type="checkbox"/> PARTIAL   <input type="checkbox"/> COMPLETE</p>	<div style="border: 2px solid black; border-radius: 50%; padding: 10px; margin: 10px 0;"> <p>The practice uses a <i>family-centered</i> approach to care (see page 2), they assess CSHCN and the needs of their families in accordance with its mission; feedback is solicited from families and influences office policies (e.g. the way things are done).</p> </div> <p style="text-align: center;"><input checked="" type="checkbox"/> PARTIAL   <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 3, a parent/ practice “advisory group” promotes <i>family-centered</i> strategies, practices and policies (e.g. enhanced communication methods or systematic inquiry of family concerns/priorities); a written, visible mission statement reflects practice commitment to quality care for CSHCN and their families.</p> <p style="text-align: center;"><input type="checkbox"/> PARTIAL   <input type="checkbox"/> COMPLETE</p>

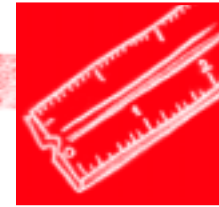


## Domain 1: Organizational Capacity: For CSHCN and Their Families

THEME:	Level 1	Level 2	Level 3	Level 4
<b>#1.1</b> <b>The Mission of the Practice</b>	<p><i>Primary care providers (PCPs)</i> at the <i>practice</i> have individual ways of delivering care to children with special health care needs CSHCN; their own education, experience and interests drive care quality.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>Approaches to the care of <i>CSHCN</i> at the <i>practice</i> are child rather than <i>family-centered</i>; office needs drive the implementation of care (e.g. the process of carrying out care).</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>The <i>practice</i> uses a <i>family-centered</i> approach to care (see page 2), they assess <i>CSHCN</i> and the needs of their families in accordance with its mission; feedback is solicited from families and influences office policies (e.g. the way things are done).</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 3, a parent/ <i>practice</i> “advisory group” promotes <i>family-centered</i> strategies, practices and policies (e.g. enhanced communication methods or systematic inquiry of family concerns/priorities); a written, visible mission statement reflects practice commitment to quality care for <i>CSHCN</i> and their families.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>
<b>#1.2</b> <b>Communication/ Access</b>	<p>Communication between the family and the <i>PCP</i> occurs as a result of family inquiry; <i>PCP</i> contacts with the family are for test result delivery or planned medical follow-up.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 1, standardized office communication methods are identified to the family by the practice (e.g. call-in hours, phone triage for questions, or provider call back hours).</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>Practice and family communicate at agreed upon intervals and both agree on “best time and way to contact me”; individual needs prompt week-end or other special appointments.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 3, office activities encourage individual requests for flexible access; access and communication preferences are documented in the care plan and used by other <i>practice</i> staff (e.g. fax, e-mail or web messages, home, school or residential care visits).</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>
<b>#1.3</b> <b>Access to the Medical Record</b> <i>Requires both MD &amp; key non-MD staff person’s perspective.</i>	<p>A policy of access to medical records is not routinely discussed with families; records are provided only upon request.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 1, it is established among staff that families can review their child’s record (but this fact is not explicitly shared with families).</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>All families are informed that they have access to their child’s record; staff facilitates access within 24-48 hours.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 3, <i>practice</i> orientation materials include information on record access; staff locate space for families to read their child’s record and make themselves available to answer questions.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>

Instructions: A) Please select and circle one level from Levels 1, 2 3, or 4 for each theme above (circle one).

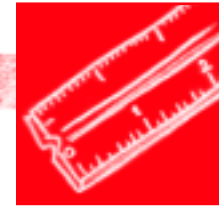
B) Then indicate whether you place your practice at a PARTIAL or COMPLETE ranking within that level (circle one).



**Domain 1: Organizational Capacity (continued): For CSHCN and Their Families**

THEME:	<i>Level 1</i>	<i>Level 2</i>	<i>Level 3</i>	<i>Level 4</i>
<p><b>#1.4 Office Environment</b> <i>Requires both MD &amp; key non-MD staff person's perspective.</i></p>	<p>Special needs concerning physical access and other visit accommodations are considered at the time of the appointment and are met if possible.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>Assessments are made during the visit of children with special health care needs and the needs of their families; any physical access &amp; other visit accommodation needs are addressed at the visit and are documented for future encounters.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 2, staff ask about any new or pre-existing physical and social needs when scheduling appointments; chart documentation is updated and staff are informed/prepared ahead of time ensuring continuity of care.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 3, key staff identify children scheduled each day with special health care needs, prepare for their visit and assess and document new needs at the visit; an office care coordinator prepares both office staff and the office environment for the visit; s/he advocates for changes (office/environmental) as needed.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>
<p><b>#1.5 Family Feedback</b> <i>Requires both MD &amp; key non-MD staff person's perspective.</i></p>	<p>Family feedback to the <i>practice</i> occurs through external mechanisms such as satisfaction surveys issued by a health plan; this information is not always shared with <i>practice</i> staff.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>Feedback from families of CSHCN is elicited sporadically by individual <i>practice</i> providers or by a suggestion box; this feedback is shared informally with other providers and staff.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>Feedback from families of CSHCN regarding their perception of care is gathered through systematic methods (e.g. surveys, focus groups, or interviews); there is a process for staff to review this feedback and to begin problem solving.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 3, an advisory process is in place with families of CSHCN which helps to identify needs and implement creative solutions; there are tangible supports to enable families to participate in these activities (e.g. childcare or parent stipends).</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>
<p><b>#1.6 Cultural Competence</b></p>	<p>The <i>primary care provider (PCP)</i> attempts to overcome obstacles of language, literacy, or personal preferences on a case by case basis when confronted with barriers to care.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 1, resources and information are available for families of the most common diverse cultural backgrounds; others are assisted individually through efforts to obtain translators or to access information from outside sources.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 2, materials are available and appropriate for non-English speaking families, those with limited literacy; these materials are appropriate to the developmental level of the child/young adult.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 3, family assessments include pertinent cultural information, particularly about health beliefs; this information is incorporated into care plans; the <i>practice</i> uses these encounters to assess patient &amp; community cultural needs.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>

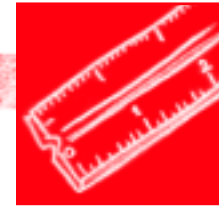




**Domain 2: Chronic Condition Management (continued): For CSHCN and Their Families**

THEME:	<i>Level 1</i>	<i>Level 2</i>	<i>Level 3</i>	<i>Level 4</i>
<p><b>#2.3</b> Continuity Across Settings</p>	<p>Communication among the <i>PCP</i>, specialists, therapists, and school happens as needs arise for <i>CSHCN</i>.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>A <i>PCP</i> makes requests and/or responds to requests from agencies or schools on behalf of <i>CSHCN</i> (e.g. <i>specific needs for accommodations, medical orders or approval of plans, or for a particular classroom placement</i>); all communication is documented.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>Systematic <i>practice</i> activities foster communication among the <i>practice</i>, family, and external providers such as specialists, schools, and other community professionals for <i>CSHCN</i>; these methods are documented and may include information exchange forms or ad hoc meetings with external providers.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 3, a method is used to convene the family and key professionals on behalf of children with more complex health concerns; specific issues are brought to this group and they all share and use a written plan of care.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>
<p><b>#2.4</b> Cooperative Management Between Primary Care Provider (<i>PCP</i>) and Specialist</p>	<p>Specialty referrals occur in response to specific diagnostic and therapeutic needs; families are the main initiators of communication between specialists and their <i>primary care provider (PCP)</i>.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 1, specialty referrals use phone, written and/or electronic communications; the <i>PCP</i> waits for or relies upon the specialists to communicate back their recommendations.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>The <i>PCP</i> and family set goals for referrals and communicate these to specialists; together they clarify co-management roles among family, <i>PCP</i> and specialists and determine how specialty feedback to the family and <i>PCP</i> is expressed, used, and shared.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 3, the family has the option of using the <i>practice</i> in a strong coordinating role; parents as partners with the <i>practice</i> manage their child's care using specialists for consultations and information (unless they decide it is prudent for the specialist to manage the majority of their child's care).</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>

Instructions: A) Please select and circle one level from Levels 1, 2 3, or 4 for each theme above (circle one).  
 B) Then indicate whether you place your practice at a PARTIAL or COMPLETE ranking within that level (circle one).



**Domain 2: Chronic Condition Management (continued): For CSHCN and Their Families**

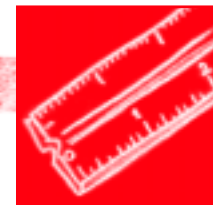
THEME:	<i>Level 1</i>	<i>Level 2</i>	<i>Level 3</i>	<i>Level 4</i>
<p><b>#2.5</b> <b>Supporting the Transition to Adult Health Care Services</b></p>	<p>Providers generally adhere to a defined pediatric age spectrum at the end of which families are provided the names of adult health care providers for primary care.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>Providers utilize a flexible approach to “aging out” so that maturing <i>CSHCN</i> may stay in the <i>practice</i> until an adult <i>PCP</i> is identified.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 2, providers anticipate transition issues in advance promoting children’s self-competence; using a developed transition timetable they take an active role in identifying an adult <i>primary care provider</i> and in transferring care.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 3 and as the transition age approaches, providers, family, and children include adult transition needs in the health care plan; specific actions may include maintaining the pediatric provider as a consultant to the new adult <i>primary care provider</i> or including the adult provider in the development of a transitional health care plan.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>
<p><b>#2.6</b> <b>Family Support</b> <i>Requires both MD &amp; key non-MD staff person’s perspective.</i></p>	<p>Families are responsible for carrying out recommendations made to them by their <i>PCP</i> when they specifically ask for family support or help.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>The <i>practice</i> responds to clinical needs; broader social and family needs are addressed and referrals to support services facilitated.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>The <i>practice</i> actively takes into account the overall family impact when a child has a chronic health condition by considering all family members in care; when families request it, staff will assist them to set up family support connections.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 3, the <i>practice</i> sponsors family support activities (e.g. skills building for parents of CSHCN on how to become a supporting parent); they have current knowledge of community or state support organizations and connect parents to them.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>

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Instructions: A) Please select and circle one level from Levels 1, 2 3, or 4 for each theme above (circle one).  
B) Then indicate whether you place your practice at a PARTIAL or COMPLETE ranking within that level (circle one).



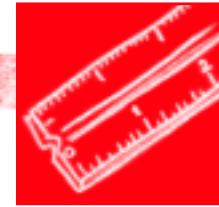
Domain 3: Care Coordination: For CSHCN and Their Families				
THEME:	<i>Level 1</i>	<i>Level 2</i>	<i>Level 3</i>	<i>Level 4</i>
<b>#3.1</b> <b>Care Coordination /Role Definition</b>	<p>The family coordinates care without specific support; they integrate office recommendations into their child's care.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>The <i>primary care provider (PCP)</i> or a staff member engages in care support activities as needed; involvement with the family is variable.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>Care coordination activities are based upon ongoing assessments of child and family needs; the <i>practice</i> partners with the family (and older child) to accomplish care coordination goals.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>Practice staff offer a set of care coordination activities (<i>*see page 3</i>), their level of involvement fluctuates according to family needs/wishes. A designated care coordinator ensures the availability of these activities including written care plans with ongoing monitoring.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>
<b>#3.2</b> <b>Family Involvement</b>	<p>The <i>PCP</i> makes medical recommendations and defines care coordination needs, the family carries these out.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>Families (and their older <i>CSHCN</i>) are regularly asked what care supports they need; treatment decisions are made jointly with the <i>PCP</i>.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 2, families (and older <i>CSHCN</i>) are given the option of centralizing care coordination activities at and in partnership with the <i>practice</i>.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 3, children &amp; families contribute to a description of care coordination activities; a care coordinator specifically develops and implements this <i>practice</i> capacity which is evaluated by families and designated supervisors.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>
<b>#3.3</b> <b>Child and Family Education</b> <i>Requires both MD &amp; key non-MD staff person's perspective.</i>	<p>Generic and specific reading materials and brochures are available from the <i>practice</i> upon request.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>Basic information relevant to <i>CSHCN</i> is offered in one on one interactions with children and families; these encounters use supportive written information with resource information.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>General information regarding having a child with special needs, and diagnosis specific information, is offered by the <i>practice</i> in a standardized manner; education anticipates potential issues and problems and refers families to other educational resources.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 3, diverse materials and teaching methods are used to address individual learning styles &amp; needs; education is broad in scope and learning outcomes are examined.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>



**Domain 3: Care Coordination (continued): For CSHCN and Their Families:**

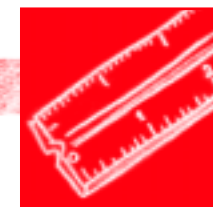
THEME:	<i>Level 1</i>	<i>Level 2</i>	<i>Level 3</i>	<i>Level 4</i>
<p><b>#3.4</b> Assessment of Needs/ Plans of Care</p>	<p>Presentation of <i>CSHCN</i> with acute problems determines how needs are addressed.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p><i>PCPs</i> identify specific needs of <i>CSHCN</i>; follow-up tasks are arranged for, or are assigned to families &amp;/or available staff.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>The child with special needs, family, and <i>PCP</i> review current child health status and anticipated problems or needs; they create/revise action plans and allocate responsibilities at least 2 times per year or at individualized intervals.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 3, the <i>PCP</i>/staff and families create a written plan of care that is monitored at every visit; the office care coordinator is available to the child and family to implement, update and evaluate the care plan.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>
<p><b>#3.5</b> Resource Information and Referrals <i>Requires both MD &amp; key non-MD staff person's perspective.</i></p>	<p>Information about resource needs and insurance coverage is gathered during regular family visit intakes; the <i>practice</i> addresses immediate family information and resource needs.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>Using a listing of community, state, and national resources which cover physical, developmental, social and financial needs the <i>practice</i> responds to family requests for information; the family seeks out additional information &amp; may share back lessons learned.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>Significant office knowledge about family and medical resources and insurance options is available; assessment of family needs leads to supported use of resources and information to solve specific problems.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 3, <i>practice</i> staff work with families helping solve resource problems; a designated care coordinator provides follow up, researches additional information, seeks and provides feedback and assists with the family to integrate new information into the care plan.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>
<p><b>#3.6</b> Advocacy</p>	<p>The <i>PCP</i> suggests that the family find support services &amp; resources outside of the <i>practice</i> when specific needs arise (e.g. diagnosis specific support groups, disability rights organizations, or Parent Support and Information Centers).</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>All families of <i>CSHCN</i> are routinely provided with basic information about Parent to Parent groups, family support, and advocacy resources during scheduled <i>practice</i> visits.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>The <i>practice</i> team identifies resources to the family for support and advocacy, facilitates the connections, and advocates on a family's behalf to solve specific problems pertinent to <i>CSHCNs</i>.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 3, this team advocates on behalf of all <i>CSHCN</i> and their families as a population and helps to create opportunities for community forums, discussions or support groups which address specific concerns.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>





**Domain 5: Data Management: For CSHCN and Their Families**

THEME:	<i>Level 1</i>	<i>Level 2</i>	<i>Level 3</i>	<i>Level 4</i>
<p><b>#5.1 Electronic Data Support</b></p>	<p><i>Primary care providers (PCPs)</i> retrieve information/data by individual chart review; electronic data are available and retrievable from payer sources only.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>Electronic recording of data is limited to billing &amp; scheduling; data are retrieved according to diagnostic code in relation to billing and scheduling; these data are used to identify specific patient groupings.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>An electronic data system includes identifiers and utilization data about children with special health care needs CSHCN; these data are used for monitoring, tracking, and for indicating levels of care complexity.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 3, an electronic data system is used to support the documentation of need, monitoring of clinical care, care plan and related coordination and the determination of outcomes (e.g. clinical, functional, satisfaction and cost outcomes).</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>
<p><b>#5.2 Data Retrieval Capacity</b></p>	<p><i>PCP</i> retrieves patient data from paper records in response to outside agency requirements (e.g. quality standards, special projects, or practice improvements).</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>The <i>practice</i> retrieves data from paper records and electronic billing and scheduling for the support of significant office changes (e.g. staffing, or allocation of resources).</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>Data are retrieved from electronic records to identify and quantify populations and to track selected health indicators &amp; outcomes.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 3, electronic data are produced and used to drive <i>practice</i> improvements &amp; to measure quality against benchmarks; (those producing and using data <i>practice</i> confidentiality).</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>



**Domain 6: Quality Improvement/Change: For CSHCN and Their Families**

THEME:	<i>Level 1</i>	<i>Level 2</i>	<i>Level 3</i>	<i>Level 4</i>
<b>#6.1 Quality Standards (structures)</b>	<p>Quality standards for children with special health care needs (CSHCN) are imposed upon the <i>practice</i> by internal or external organizations.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 1, an individual staff member participates on a committee for improving processes of care at the <i>practice</i> for CSHCN. This person communicates and promotes improvement goals to the whole <i>practice</i>.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>The <i>practice</i> has its own systematic quality improvement mechanism for CSHCN; regular provider and staff meetings are used for input and discussions on how to improve care and treatment for this population.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 3, the <i>practice</i> actively utilizes quality improvement (QI) processes; staff and parents of CSHCN are supported to participate in these QI activities; resulting quality standards are integrated into the operations of the <i>practice</i>.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>
<b>#6.2 Quality Activities (processes)</b>	<p><i>Primary care providers (PCPs)</i> have completed courses or have had an adequate orientation to continuous quality improvement methods.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>Corporate owners, administrators or payers identify <i>practice</i> deficits and set goals for improvements; <i>practice</i> providers and staff are identified to fix problems with limited participation in the process.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>Periodic formal, and informal quality improvement activities gather staff input about <i>practice</i> improvement ideas and opportunities for CSHCN; efforts are made toward related changes and improvements for this population.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>	<p>In addition to Level 3, the <i>practice</i> systematically learns about CSHCN &amp; draws upon family input; together the <i>practice</i> and families design and implement office changes that address needs and gaps; they then study their outcomes and act accordingly.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p>

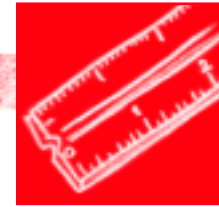
Please make certain you have chosen a Level (1-4).

Also indicate whether your *practice* performance within that level is “partial” (some activity within that level) or “complete” (all activity within the level).

Thank You

Instructions: A) Please select and circle one level from Levels 1, 2 3, or 4 for each theme above (circle one).

B) Then indicate whether you place your practice at a PARTIAL or COMPLETE ranking within that level (circle one).

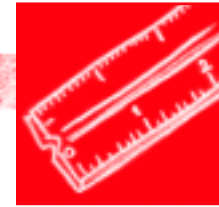


## Summary

A summary of your comments can go here (e.g. likes, dislikes, what we left out, stress too much, etc.).

You may want to jot down any examples of forms, tools, charting or ways that you “do things” that you particularly want us to know about.

Other remarks:



## THE MEDICAL HOME *FAMILY* INDEX:

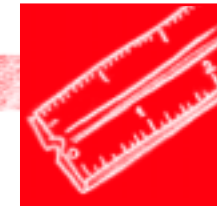
### Measuring the Organization and Delivery of Primary Care For Children with Special Health Care Needs

A community-based primary care “medical home” is a health care practice in your community that is completely responsive to you and your child’s needs. This is especially so when your child has a chronic health condition or disability. A group at the Hood Center for Children and Families at Children’s Hospital at Dartmouth Hitchcock Medical Center (New Hampshire) has been asked to create a Medical Home Index to find out about the medical “homeness” of a health care practice or office.

Your child’s primary care provider fills out The Medical Home Index; this set of questions looks at the care activities that make the medical home “come alive” in practice. Health care providers will rate the care that they offer to children with special health care needs and their families. They will comment on how they partner with families in their children’s care and provide care coordination and other needed supports.

No questionnaire truly captures the medical “homeness” of a practice unless information is gathered from families. You are being asked to fill out this Medical Home Family Index and to report on the services and supports that your child actually receives. The Medical Home Family Index uses twenty-five questions to capture the family perspective, please try to answer each question to the best of your ability. Thank-you for your willingness to complete this set of questions and for your thoughtful comments written at its end.

Please turn to the next page ...

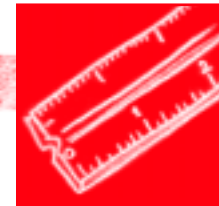


## THE MEDICAL HOME *FAMILY* INDEX:

### Measuring the Organization and Delivery of Primary Care For Children with Special Health Care Needs

The following questions refer to the care that your child receives from his/her pediatrician or primary care provider (PCP) and the staff who work in their office. Next to each question circle the response that best describes your experience of care for your child.

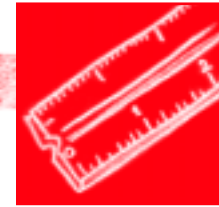
1. Through this practice/office I can get the health care that my child needs when we need it (including after office hours, on weekends and holidays).	Never	Sometimes	Often	Always
2. When I call the office: (please answer for a, b, c, and d): a) Staff know who we are b) Staff respect our needs and requests c) Staff remember any special needs or supports that we have asked for d) We are asked if there are any new needs requiring attention	Never Never Never Never	Sometimes Sometimes Sometimes Sometimes	Often Often Often Often	Always Always Always Always
3. My primary care provider (PCP) uses helpful ways to communicate (e.g. explaining terms clearly, helping us prepare for visits, e-mail, or encouraging our questions): a) With me b) With my child (If (b) does not apply to your child ✓here ___)	Never Never	Sometimes Sometimes	Often Often	Always Always
4. My PCP asks me to share with him/her my knowledge and expertise as the parent or caregiver of a child with special health care needs (CSHCN).	Never	Sometimes	Often	Always
5. I am asked by our PCP how my child's condition affects our family (e.g. the impact on siblings, the time my child's care takes, lost sleep, extra expenses, etc.).	Never	Sometimes	Often	Always
6. My PCP listens to my concerns and questions?	Never	Sometimes	Often	Always
7. Planning of care for my child includes: (please answer for a, b, c and d): a) The writing down of key information (e.g. recommendations, treatments, phone #) b) Setting short term goals (e.g. for the next three months) c) Setting long term goals (e.g. for the next year or more) d) Thorough follow-up with plans created	Never Never Never Never	Sometimes Sometimes Sometimes Sometimes	Often Often Often Often	Always Always Always Always
8. My primary care provider and staff work with our family to create a written care plan for my child. (If your answer is "never", then skip to Question # 11)	Never	Sometimes	Often	Always



9. I receive a copy of my child's care plan with all updates and changes.	Never	Sometimes	Often	Always
10. My primary care provider (PCP) and his/her office staff (please answer a, b and c): a) Use and follow through with care plans they have created b) Use a care plan to help follow my child's progress c) Review and update the care plan with me regularly	Never Never Never	Sometimes Sometimes Sometimes	Often Often Often	Always Always Always
11. My PCP has a staff person(s) or a "care coordinator" who will: a) Help me with difficult referrals, payment issues, and follow-up activities b) Help to find needed services (e.g. transportation, durable equipment or home care) c) Make sure that the planning of care meets my child and my families needs d) Help each person involved in my child's care to communicate with each other (with my consent).	Never Never Never Never	Sometimes Sometimes Sometimes Sometimes	Often Often Often Often	Always Always Always Always
12. When or if I ask for it, our PCP or office staff help me to: a) Explain my child's needs to other health professionals b) Get my child's school, early care providers or others to understand his/her condition (If (b) does not apply to your child ✓ here ___)	Never Never	Sometimes Sometimes	Often Often	Always Always
13. Someone at the office is available to review my child's medical record with me when or if I ask to see it.	Yes		No	
14. Office providers or staff who are involved with my child's care know about their condition, history, and our concerns and priorities.	Yes		No	
15. My PCP or his/her office staff sponsor activities to support my family (e.g. support groups, parent skill building or how to support other parents).	Yes		No	
16. Office staff help me to connect with family support organizations and informational resources in our community and state.	Yes		No	
17. My PCP is a strong advocate for the rights and services important to children with special health care needs and their families.	Yes		No	
18. My PCP assists me in finding adult health care services for my child. (Check here if due to your child's age this does not apply ____).	Yes		No	



# Center for Medical Home Improvement



19. My primary care provider (PCP) and office staff organize and attend team meetings about my child's plan of care that include us and outside providers (when needed).	Yes	No		
20. My PCP and office staff organize and attend events to talk about concerns and needs common to all children with special health care needs (CSHCN) and their families.	Yes	No		
21. I have seen changes made at the office as a result of my suggestions or those made by other families.	Yes	N		
22. I know the practice has conducted surveys, focus groups, or discussions with families (in the last two years) to determine if they are satisfied with their children's care.	Yes	No		
23. From my experience, I believe that my PCP and the staff at his/her office have a commitment to provide the quality care and family supports that we need.	Yes	No		
24. The behavior which best demonstrates the needed care and compassion I need from my child's PCP is _____ (write in here).	Comments:			
25. The frequency that I observe and experience this behavior (in #24) is?	Never	Sometimes	Often	Always

40

*Would you please go back over this Family Index to check for unanswered questions; try to answer them to the best of your ability.*

Please write down:

The name of the practice where you go for your child's care: \_\_\_\_\_

The name of your child's primary care provider: \_\_\_\_\_

The length of time your child has been cared for by this practice? \_\_\_\_\_ Your child's age: \_\_\_\_\_

Your name, address, & social security #: \_\_\_\_\_

Address: \_\_\_\_\_ SS# \_\_\_\_\_

**(Optional)** What is the racial/ethnic background with which you most closely identify?

White, Non-Hispanic    African American    Hispanic    Native American/American Indian/Alaskan Native    Asian    Other (specify)

May we have your permission to contact you further about this project?    Yes    No

Other comments you would like to make? (Feel free to use the other side) \_\_\_\_\_ *Thank You for Sharing Your Experiences*