



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 primary care practices to better serve *CSHCN* in their communities.

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) _____ % Public insurance only (Medicaid/CHIP) | 2) _____ % Private & Medicaid | |
| 3) _____ % Self/No pay | 4) _____ % Private insurance only | 5) _____ % Other |

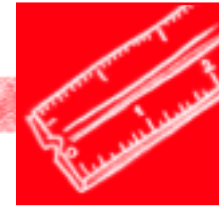
How familiar/knowledgeable are you about the concept of a medical home as defined by the American Academy of Pediatrics?

- | | |
|---|---|
| 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 US Maternal and Child Health Bureau?

- | | |
|--|--|
| 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 |

(Note: Any italicized words are defined in the glossary on page 13)



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.
- 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 EXAMPLE and Their Families | | | | |
|--|---|---|---|---|
| THEME: | <i>Level 1</i> | <i>Level 2</i> | <i>Level 3</i> | <i>Level 4</i> |
| #1.1 The Mission of the Practice | <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. <input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE | 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). <input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE | <div style="border: 2px solid black; border-radius: 15px; padding: 5px;"> The practice uses a family-centered approach to care (see page13), 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). </div> <input checked="" type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE | 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. <input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE |

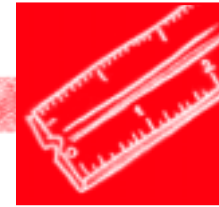


Domain 1: Organizational Capacity: For CSHCN and Their Families

| THEME: | <i>Level 1</i> | <i>Level 2</i> | <i>Level 3</i> | <i>Level 4</i> |
|--|--|---|--|--|
| #1.1 The Mission of the Practice | <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 practice uses a family-centered approach to care (see page13), 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> <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 CSHCN and their families.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p> |
| #1.2 Communication/ Access | <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 practice 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> |
| #1.3 Access to the Medical Record <i>Requires both MD & 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, practice 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> |

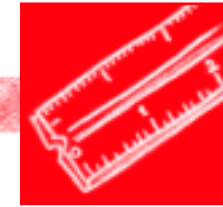
Instructions: A) Please select and circle one level from Levels 1, 2 3, or 4 for each theme above (circle one).

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>#1.4 Office Environment <i>Requires both MD & 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 & 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>#1.5 Family Feedback <i>Requires both MD & 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 practice staff.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p> | <p>Feedback from families of <i>CSHCN</i> is elicited sporadically by individual practice 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 <i>CSHCN</i> 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 <i>CSHCN</i> 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>#1.6 Cultural Competence</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 & community cultural needs.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p> |

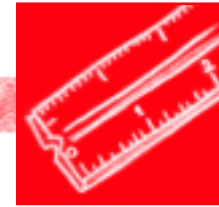


Domain 1: Organizational Capacity (continued): For CSHCN and Their Families

| THEME: | <i>Level 1</i> | <i>Level 2</i> | <i>Level 3</i> | <i>Level 4</i> |
|---|--|---|--|--|
| #1.7 Staff Education <i>Requires both MD & key non-MD staff person's perspective.</i> | For all staff, an orientation to internal office practices, procedures and policies is provided. <input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE | In addition to Level 1, the practice supports (paid time/ tuition support) continuing education for all staff in the care of CSHCN (children with special health care needs). <input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE | In addition to Level 2, educational information on community-based resources for CSHCN, including diagnosis specific resource information, is available for all staff. <input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE | In addition to Level 3, families of CSHCN are integrated into office staff orientations and educational opportunities as teachers or “family faculty”; support for families to take this role is provided. <input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE |

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

| THEME: | <i>Level 1</i> | <i>Level 2</i> | <i>Level 3</i> | <i>Level 4</i> |
|---|---|---|--|--|
| #2.1 Identification of Children in the Practice with Special Health Care Needs | Children with special health care needs (CSHCN) can be counted informally (e.g. by memory or from recent acute encounter); comprehensive identification can be done through individual chart review only. <input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE | Lists of children with special health care needs are extracted electronically by diagnostic code. <input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE | A CSHCN list is generated by applying a definition (see pg. 13), the list is used to enhance care +/- define practice activities (e.g. to flag charts and computer databases for special attention or identify the population and its subgroups). <input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE | In addition to Level 3, diagnostic codes for CSHCN are documented, problem lists are current, and complexity levels are assigned to each child; this information creates an accessible practice database. <input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE |
| #2.2 Care Continuity | Visits occur with the child's own primary care provider (PCP) as a result of acute problems or well child schedules; the family determines follow up. <input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE | Non-acute visits occur with families and their PCP to address chronic condition care; the PCP determines appropriate visit intervals; follow-up includes communication of tasks to staff and of lab and medical test results to the family. <input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE | The team (including PCP, family, and staff) develops a plan of care for CSHCN which details visit schedules and communication strategies; home, school and community concerns are addressed in this plan. Practice back up/cross coverage providers are informed by these plans. <input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE | In addition to Level 3, the practice/teams use condition protocols; they include goals, services, interventions and referral contacts. A designated care coordinator uses these tools and other standardized office processes which support children and families. <input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE |



| 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> |
| #2.3 Continuity Across Settings | <p>Communication among the PCP, specialists, therapists, and school happens as needs arise for CSHCN.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p> | <p>A PCP makes requests and/or responds to requests from agencies or schools on behalf of CSHCN (e.g. specific needs for accommodations, medical orders or approval of plans, or for a particular classroom placement); all communication is documented.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p> | <p>Systematic practice activities foster communication among the practice, family, and external providers such as specialists, schools, and other community professionals for CSHCN; 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> |
| #2.4 Cooperative Management Between Primary Care Provider (PCP) and Specialist | <p>Specialty referrals occur in response to specific diagnostic and therapeutic needs; families are the main initiators of communication between specialists and their primary care provider (PCP).</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 PCP 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 PCP and family set goals for referrals and communicate these to specialists; together they clarify comanagement roles among family, PCP and specialists and determine how specialty feedback to the family and PCP 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> |

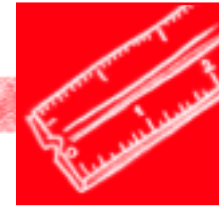
Instructions: A) Please select and circle one level from Levels 1, 2 3, or 4 for each theme above (circle one).

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



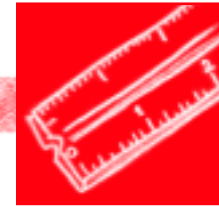
Domain 2: Chronic Condition Management (continued): For CSHCN and Their Families

| THEME: | <i>Level 1</i> | <i>Level 2</i> (in addition to level 1) | <i>Level 3</i> (in addition to level 2) | <i>Level 4</i> (in addition to level 3) |
|--|--|---|---|--|
| <p># 2.5.1*</p> <p>Supporting the Transition to Adulthood</p> <p><i>* transition measure revised August, 2006.</i></p> | <p>Pediatric and adolescent primary care providers (PCPs) adhere to defined health maintenance schedules for youth with special health care needs in their practice.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p> | <p>Pediatric and adolescent PCPs offer age appropriate anticipatory guidance for specific youth & families related to their chronic condition, self-care, nutrition, fitness, sexuality, and other health behavior information.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p> | <p>Pediatric and adolescent PCPs support youth & family to manage their health using a transition timeline & developmental approach; they assess needs & offer culturally effective guidance related to:</p> <ul style="list-style-type: none"> • health & wellness • education & vocational planning • guardianship and legal & financial issues • community supports & recreation <p>When youth transition from pediatrician to adult provider: Pediatricians help to identify an adult PCP and sub-specialists and offer ongoing consultation to youth, family and providers during the transition process. Adult Providers offer an initial “welcome” visit and a review of transition goals.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p> | <p>Progressively from age 12, youth, family and PCP develop a written transition plan within the care plan; it is made available to families and all involved providers.</p> <p>Youth and families receive coordination support to link their health and transition plans with other relevant adolescent and adult providers/services/agencies (e.g. sub-specialists, educational, financial, insurance, housing, recreation employment and legal assistance).</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p> |
| <p>#2.6 Family Support</p> <p><i>Requires both MD & key non-MD staff person’s perspective.</i></p> | <p>Families are responsible for carrying out recommendations made to them by their PCP 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> |



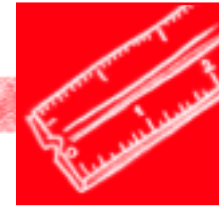
Domain 3: Care Coordination: For CSHCN and Their Families

| THEME: | <i>Level 1</i> | <i>Level 2</i> | <i>Level 3</i> | <i>Level 4</i> |
|--|---|---|--|--|
| #3.1 Care Coordination /Role Definition | <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 practice 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 (*see page 14), 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> |
| #3.2 Family Involvement | <p>The PCP 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 CSHCN) 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 CSHCN) 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 & families contribute to a description of care coordination activities; a care coordinator specifically develops and implements this practice capacity which is evaluated by families and designated supervisors.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p> |
| #3.3 Child and Family Education <i>Requires both MD & 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 CSHCN 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 practice 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 & 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>#3.4 Assessment of Needs/ Plans of Care</p> | <p>Presentation of CSHCN with acute problems determines how needs are addressed.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p> | <p>PCPs identify specific needs of CSHCN; follow-up tasks are arranged for, or are assigned to families &/or available staff.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p> | <p>The child with special needs, family, and PCP 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 PCP/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>#3.5 Resource Information and Referrals <i>Requires both MD & 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 practice 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 practice responds to family requests for information; the family seeks out additional information & 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, practice 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>#3.6 Advocacy</p> | <p>The PCP suggests that the family find support services & resources outside of the practice 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 CSHCN are routinely provided with basic information about Parent to Parent groups, family support, and advocacy resources during scheduled practice visits.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p> | <p>The practice 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 CSHCNs.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p> | <p>In addition to Level 3, this team advocates on behalf of all CSHCN 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> |

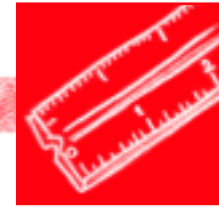


Domain 4: Community Outreach: For CSHCN and Their Families

| THEME: | <i>Level 1</i> | <i>Level 2</i> | <i>Level 3</i> | <i>Level 4</i> |
|--|---|--|---|---|
| <p>#4.1 Community Assessment of Needs for CSHCN</p> | <p><i>Primary care provider (PCP)</i> awareness of the population of children with special health care needs <i>CSHCN</i> in their community is directly related to the number of children for whom the provider cares.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p> | <p>The practice learns about issues and needs related to <i>CSHCN</i>s from key community informants; providers blend this input with their own personal observations to make an informal and personal assessment of the needs of <i>CSHCN</i> in their community.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p> | <p>In addition to Level 2, providers raise their own questions regarding the population of <i>CSHCN</i> in their practice community(ies); they seek pertinent data and information from families and local/state sources and use data to inform practice care activities.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p> | <p>In addition to Level 3, at least one clinical practice provider participates in a community-based public health need assessment about <i>CSHCN</i>, integrates results into practice policies, and shares conclusions about population needs with community & state agencies.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p> |
| <p>#4.2 Community Outreach to Agencies and Schools.</p> | <p>When the family, school or agency request interactions with the <i>primary care provider (PCP)</i> on behalf of a child's community needs, the provider responds, thereby establishing the practice as a resource.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p> | <p>In addition to Level 1, when a community agency or school requests technical assistance or education from the practice about <i>CSHCN</i>, the practice communicates, collaborates, and educates based upon availability and interest.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p> | <p>The practice initiates outreach to community agencies and schools that directly serve <i>CSHCN</i> (e.g. through representation on one or more advisory boards or committees); they advocate for improved community services and inter-organizational collaboration & communication.</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p> | <p>In addition to Level 3, the <i>practice</i> identifies needs of <i>CSHCN</i> & their families; they work with families to sponsor activities that raise community awareness to resource and support needs (e.g. specialized home care, respite care recreation opportunities, or improving home/school/ provider communication).</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p> |

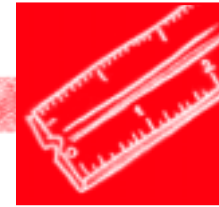
Instructions: A) Please select and circle one level from Levels 1, 2 3, or 4 for each theme above (circle one).

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



Domain 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> |
|---|--|--|---|---|
| #5.1 Electronic Data Support | <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 & 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> |
| #5.2 Data Retrieval Capacity | <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 & 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 practice improvements & to measure quality against benchmarks; (those producing and using data practice confidentiality).</p> <p><input type="checkbox"/> PARTIAL <input type="checkbox"/> COMPLETE</p> |

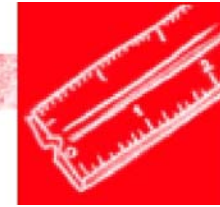


| Domain 6: Quality Improvement/Change: For CSHCN and Their Families | | | | |
|--|--|--|---|--|
| THEME: | <i>Level 1</i> | <i>Level 2</i> | <i>Level 3</i> | <i>Level 4</i> |
| #6.1 Quality Standards (structures) | <p>Quality standards for children with special health care needs (CSHCN) are imposed 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 practice.</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> |
| #6.2 Quality Activities (processes) | <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 & 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).



The Medical Home Index

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

DEFINITIONS OF CORE CONCEPTS (Words in *italics* throughout the document are defined below.)

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:

A medical home is a community-based primary care setting which provides and coordinates high quality, planned, family-centered health promotion and chronic condition management. According to the American Academy of Pediatrics (AAP) a “medical home” is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent.

Family-Centered Care (US Maternal and Child Health Bureau, 2004):

Family-centered care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-centered care is the standard of practice which results in high quality services.



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:

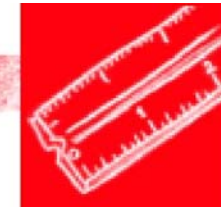
Care and services performed in partnership with the family and providers by health professionals to:

- 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.



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

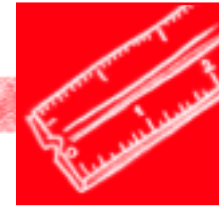
United States Maternal and Child Health Bureau - (USMCHB):

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.



Center for
Medical Home
Improvement



Summary/Notes