



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.

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; your input will help your primary care provider improve the quality of care provided for children with special health care needs at his or her practice.

[Excerpt from The Medical Home Family Index, developed by the Center for Medical Home Improvement, Crotched Mountain, 1 Verney Drive, Greenfield, New Hampshire 03047 as a result of funding from the United States Maternal and Child Health Bureau (6 HO2 MC 00087-01-01 and 6 HO2 MC 00062-04--3).]



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The following questions refer to the care that your child receives from his/her pediatrician or primary care provider (PCP) and their office staff. These questions are organized to address the domains of a Medical Home defined in the Medical Home Index, which is completed by the PCP and his/her staff. Next to each question circle the response that best describes your experience of care for your child.

DOMAIN 1: Organizational Capacity: For CSHCN and Their Families				
A practice's Organizational Capacity is the ability of the practice to respond to a broad range of variables that exemplify family-centered care.				
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 <input type="checkbox"/>)	Never Never	Sometimes Sometimes	Often Often	Always Always
4. 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	
5. Office providers or staff who are involved with my child's care know about their condition, history, and our concerns and priorities.	Yes		No	
6. I have seen changes made at the office as a result of my suggestions or those made by other families.	Yes		No	
7. 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	
8. 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	

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

Chronic Condition Management encompasses a set of special services relating to the extra layers of care and care continuity for children whose chronic condition represents a significant impact upon their lives and upon the lives of their families.

9. 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
10. 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 <input type="checkbox"/>)	Never Never	Sometimes	Often	Always
11. 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	
12. Office staff help me to connect with family support organizations and informational resources in our community and state.	Yes		No	
13. 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 <input type="checkbox"/>)	Yes		No	
14. 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	

DOMAIN 3: Care Coordination: For CSHCN and Their Families

Care Coordination is the identification of needs and the actions taken to address those needs. It is essential for successfully responding to many of the needs that children with special health care needs and their families experience on a daily basis.

15. 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
16. My PCP listens to my concerns and questions.	Never	Sometimes	Often	Always
17. 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

18. 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
19. I receive a copy of my child’s care plan with all updates and changes.	Never	Sometimes	Often	Always
20. My primary care provider (PCP) and his/her office staff (please answer for 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
21. My PCP has a staff person(s) or a “care coordinator” who will (please answer for a, b, c, and d): 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 family’s need. 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
22. My PCP is a strong advocate for the rights and services important to children with special health care needs and their families.	Yes		No	
DOMAIN 4: Community Outreach: For CSHCN and Their Families				
Community Outreach focuses on how the practice can address primary health care concerns of children with special health care needs within the community. It includes both the direct relationships the practice has with community agencies/service providers as well as the practice’s general awareness about children with special health care needs within the community.				
23. 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	
COMMENTS				
24. The behavior which best demonstrates the care and compassion I need from my child’s PCP is: Comments: (write in here)				
25. The frequency that I observe and experience this behavior (in #24) is?	Never	Sometimes	Often	Always

Please go back over this Family Index to check for any unanswered questions and 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 _____

(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)

Additional comments: (If you need additional space, please use the other side of this form) _____

Thank You for Sharing Your Experiences!