

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 ...



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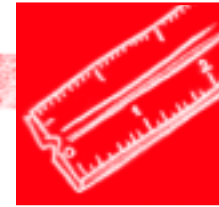
Measuring the Organization and Delivery of Primary Care For Children with Special Health Care Needs

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	



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

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: _____

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