The Medical Home
Family Index and Survey

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Center for
Medical Home
Improvement

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	Never	Sometimes	Often	Always
b) Staff respect our needs and requests	Never	Sometimes	Often	Always
c) Staff remember any special needs or supports that we have asked for	Never	Sometimes	Often	Always
d) We are asked if there are any new needs requiring attention	Never	Sometimes	Often	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	Never	Sometimes	Often	Always
b) With my child (If (b) does not apply to your child ✔here ___)	Never	Sometimes	Often	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 #)	Never	Sometimes	Often	Always
b) Setting short team goals (e.g. for the next three months)	Never	Sometimes	Often	Always
c) Setting long term goals (e.g. for the next year or more)	Never	Sometimes	Often	Always
d) Thorough follow-up with plans created	Never	Sometimes	Often	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	Never	Sometimes	Often	Always
b) Use a care plan to help follow my child's progress	Never	Sometimes	Often	Always
c) Review and update the care plan with me regularly	Never	Sometimes	Often	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	Never	Sometimes	Often	Always
b) Help to find needed services (e.g. transportation, durable equipment or home care)	Never	Sometimes	Often	Always
c) Make sure that the planning of care meets my child and my families needs	Never	Sometimes	Often	Always
d) Help each person involved in my child's care to communicate with each other (with my consent).	Never	Sometimes	Often	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	Never	Sometimes	Often	Always
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	Sometimes	Often	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: _____

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*

Center for Medical Home Improvement
Family/Caregiver Survey

Today's date: __/__/__

My child is a (1) ____ Boy (2) ____Girl

Child's date of birth (or age in total months):_____

Each of the following questions (unless otherwise stated) refers to right now or in the past 12 months. When questions do not apply to your family or child, circle or write NA (not applicable).

In your opinion what is your child's **(most)** primary medical condition? (**Circle only one**)

1) Arthritis 2) Asthma 3) Attention deficit/hyperactivity 4) Autism/pervasive development disorder 5) Blindness/trouble seeing 6) Cerebral palsy 7) Chronic ear infection 8) Cleft lip/palate 9) Cystic fibrosis	10) Deafness/trouble hearing 11) Depression 12) Diabetes 13) Down syndrome 14) Eating disorder 15) Heart disease or heart defect 16) Hemophilia 17) HIV/AIDS 18) Permanent deformity of arms/legs 19) Kidney disease 20) Leukemia/Cancer 21) Mental retardation	22) Muscular dystrophy 23) Obesity 24) Recurrent urinary tract infection 25) Seizure disorder 26) Severe allergies 27) Severe scoliosis 28) Sickle cell disease 29) Spina bifida 30) Other (specify below) _____ _____ _____

Select from the list above (1-29) any additional conditions that your child has, write the number of the condition (s) on the lines below. If your child's additional condition(s) are not on the list, please also write it/them on the lines below.

a._____ d._____

b._____ e._____

c._____ f._____

Caring for Your Child

The next five questions ask about your child's health needs and whether your child has a health condition. A **health condition** can be physical, mental or behavioral. **Health conditions** may affect a child's development, daily function or need for services.

1. Does your child currently need or use **medicine prescribed by a doctor** (other than vitamins)?
   - ❒ Yes → Go to Question 1a
   - ❒ No → Go to Question 2

   1a. Is this because of ANY medical, behavioral or other health condition?
   - ❒ Yes → Go to Question 1b
   - ❒ No → Go to Question 2

   1b. Is this a condition that has lasted or is expected to last for *at least* 12 months?
   - ❒ Yes
   - ❒ No

2. Does your child need or use more **medical care, mental health or educational services** than is usual for most children of the same age?
   - ❒ Yes → Go to Question 2a
   - ❒ No → Go to Question 3

   2a. Is this because of ANY medical, behavioral or other health condition?
   - ❒ Yes → Go to Question 2b
   - ❒ No → Go to Question 3

   2b. Is this a condition that has lasted or is expected to last for *at least* 12 months?
   - ❒ Yes
   - ❒ No

3. Is your child **limited or prevented** in any way in his or her ability to do the things most children of the same age can do?
   - ❒ Yes → Go to Question 3a
   - ❒ No → Go to Question 4

   3a. Is this because of ANY medical, behavioral or other health condition?
   - ❒ Yes → Go to Question 3b
   - ❒ No → Go to Question 4

   3b. Is this a condition that has lasted or is expected to last for *at least* 12 months?
   - ❒ Yes
   - ❒ No

4. Does your child need or get **special therapy**, such as physical, occupational or speech therapy?
   - ❒ Yes → Go to Question 4a
   - ❒ No → Go to Question 5

   4a. Is this because of ANY medical, behavioral or other health condition?
   - ❒ Yes → Go to Question 4b
   - ❒ No → Go to Question 5

   4b. Is this a condition that has lasted or is expected to last for *at least* 12 months?
   - ❒ Yes
   - ❒ No

5. Does your child have any kind of emotional, developmental or behavioral problem for which he or she needs or gets **treatment or counseling**?
   - ❒ Yes → Go to Question 5a
   - ❒ No

   5a. Has this problem lasted or is it expected to last for *at least* 12 months?
   - ❒ Yes
   - ❒ No

6. In general, would you say your child's **health** is: (Circle one)

   (1) Excellent (2) Good (3) Fair (4) Poor

7. Is there a place that your child usually goes to when he/she is sick or you need advice about his/her health?

   1) Yes 2) No 3) There is more than one place

8. A personal doctor or nurse is the health provider who knows your child best. Do you have one person that you think of as your child's personal doctor or nurse?

   1) Yes 2) No 3) Don't know

9. How **difficult** is it to take care of your child's chronic health condition(s) or disability?

   (1) Not at all difficult (3) Some what difficult
   (2) A little difficult (4) Very difficult

10. During the last 3 months, how often have you worried about your child's **health**? (Circle One)

    (1) None of the time (4) Most of the time
    (2) A little of the time (5) All of the time
    (3) Some of the time

11. During the last 3 months, how often have you worried about the impact of your child's chronic health condition or disability **upon his or her siblings**?

(1) None of the time
(2) A little of the time
(3) Some of the time
(4) Most of the time
(5) All of the time
(6) Does not apply to your family

12. Overall, how would you rank the **severity** of your child's condition or problem?
Please pick a number from "0" to "10" where "0" is the mildest severity, "10" is the most severe.

0 1 2 3 4 5 6 7 8 9 10

Mildest severity **Most severe**

13. Which of the following statements best describes your child's health care needs?

1) Child's health care needs change all the time
2) Child's health care needs change only once in awhile
3) Child's health care needs are usually stable
4) None of the above
5) Don't know

14. How would you measure the level of stress experienced over the last year as a result of caring for your child?
Please pick a number from "0" to "10" where "0" represents very low stress and "10" is for extremely high stress.

0 1 2 3 4 5 6 7 8 9 10

Very low stress **Extremely high stress**

15. Does your child's doctor or office staff help to alleviate this stress (e.g. with services, supports, or referrals to other resources)?

1) Always
2) Often
3) Sometimes
4) Never

16. During the last month, how often have your emotions (such as feeling depressed or anxious) interfered with your work, social activities, or daily routine?

1) None of the time
2) A little of the time
3) Some of the time
4) Most of the time
5) All of the time

17. During the past 12 months (1 year ago today) how many days did your child miss school because of their chronic health condition or disability?

Write in the number of days _____ (a typical school year has ~185)

17a. Also indicate:

(1) None (no days absent)
(2) Did not go to school
(3) Home schooled
(4) Don't know

18. Do you have any of the following specific concerns for your child?
(Circle the number under the response that best describes your concern):

	Never	Seldom	Sometimes	Often	Always	NA
18a. Growth and development	1	2	3	4	5	6
18b. Ability to learn	1	2	3	4	5	6
18c. Participation in activities of his/her age group	1	2	3	4	5	6
18d. Ability to make healthy choices (e.g. activity, rest, diet, medicines)	1	2	3	4	5	6
18e. Self esteem/emotional well being	1	2	3	4	5	6
18f The future	1	2	3	4	5	6

NA (not applicable)

19. How would you estimate the current overall **severity** of your child's special health care needs?
(1) Minimal
(2) Mild
(3) Moderate
(4) Severe

20. Are things the same from day to day with your child, or is it hard to know what to expect?
(1) Pretty much the same day to day
(2) Occasional surprises
(3) Lots of unexpected changes
(4) Very unpredictable one day to the next

Using the Health Care System

21. How satisfied are you with the care coordination provided outside of the family that you receive for your child?
(1) Very satisfied
(2) Somewhat satisfied
(3) Dissatisfied
(4) Very dissatisfied
(5) NA (not applicable)

22. During the past year, how many times was your child seen by your child's primary care provider?
(1) None at all
(2) 1 - 3 times
(3) 4 - 10 times
(4) More than 10 times
(5) NA (not applicable)

23. During the past year, how many times was your child seen by a specialist/specialty clinic?
(1) None
(2) 1 - 3 times
(3) 4 - 10 times
(4) More than 10 times

24. During the past year, how many times did your child require care in the emergency room?
(1) None
(2) 1 - 3 times
(3) 4 - 10 times
(4) More than 10 times

25. During the past year, how many separate times did your child have to stay in the hospital overnight?

(1) None at all
(2) 1 - 3 times
(3) 4 - 7 times
(4) 8 - 10 times
(5) More than 10 times

26. In the past 3 months, how many days have you or anyone in your family had to **stay home from work** because of your child's chronic health condition(s) or disability?

(1) None
(2) 1 – 5 work days
(3) 6 - 16 work days
(4) 16 or more work days
(5) No one is employed

Family Care Coordination

Parents of children with chronic health conditions often do a variety of activities to coordinate care for their child. Some parents are new at this, others have been coordinating their child's care for years. Listed below are some of the care activities parents often do. Please read each activity and **circle** the response that best describes you and your family.

	Always	Often	Some-Times	Rarely	Never	NA
27. Involving my child in regular recreational activities in the community.	1	2	3	4	5	6
28. Finding the help I need to coordinate services for my child.	1	2	3	4	5	6
29. Finding other parents to talk to who have children with similar conditions.	1	2	3	4	5	6
30. Describing how this medical condition affects my child's growth and development.	1	2	3	4	5	6
31. Taking action to correct poor care and services my child receives.	1	2	3	4	5	6
32. (*If school age or older*) Getting my child to take an active role as possible in health discussions and in decision making.	1	2	3	4	5	6
33. Communicating my concerns about my child's health needs to most professionals.	1	2	3	4	5	6
34. Getting medical professionals to give us information that we can understand.	1	2	3	4	5	6

Practice Satisfaction: How would you rate the practice for each of the following qualities?

Please circle one number on each line.	**Excellent**	**Very Good**	**Good**	**Fair**	**Poor**	**NA**
35. The length of time waiting at the office.	1	2	3	4	5	6
36. Clear directions for who to contact or where to go for aspects of your child's condition when they are not ill.	1	2	3	4	5	6
37. Provider(s) and staff have regular contact with your child's school staff.	1	2	3	4	5	6

38. How many **additional** children live in your home?
1) none 2)one 3) two 4) three 5) four 6) five 7) six or more

39. Has anyone in your family been **unable to work** outside the home due to your child's health condition or disability?
1) yes 2) no

40. What do you or your child currently need that you are ***not*** receiving?

Family Information	**Yes**	**No**	**Don't Know**
41. Do you have health insurance for yourself?	1	2	DK
42. Do you have health insurance for your child?	1	2	DK
43. Do you have Medicaid for your child?	1	2	DK
44. Do you have supplemental security income (SSI)?	1	2	DK
45. Do you receive any other assistance from the state (e.g. special medical services, children with special needs)?	1	2	DK
46. Do you have regular out of pocket health expenses (over $50/month or over $600/year) to care for your child's health condition or disability (<u>not</u> including insurance deductibles or co-payments)?	1	2	DK

47. Are out of pocket expenses related mostly to (circle all that apply):

1. Equipment
2. Supplies
3. Medications
4) Family support
5) Counseling
6) Respite care
7) Other _____ (write in)

Please use the space below to express your thoughts about this survey or any of the areas it has caused you to think about.

Thank you for your help and time in completing this survey

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(Questions 1-5 are from the FACCT – Foundation for Accountability CAMHI/ Chronic Condition Screener)