

## THE ILLINOIS MEDICAL HOME FAMILY FEEDBACK TOOL\*

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 with special health care needs receives from his/her health care provider and their office staff. Next to each question circle the response that best describes your experience of care for your child. (Your child's "health care provider" is his/her doctor, nurse practitioner or other health professional.)

<b>Organizational Capacity of the Practice</b>				
1. Through this practice/office, (please answer a and b): a) I can get the health care that my child needs when we need it (including after office hours, on weekends and holidays). b) Adequate time is allowed to answer all my questions.	Always	Often	Sometimes	Never
	Always	Often	Sometimes	Never
2. When I call the office (please answer for a, b, c, d, e, and f): 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. e) The office's answering service is reliable and forwards my calls to my health care provider. f) I can rely on my health care provider to return my calls after office hours.	Always	Often	Sometimes	Never
	Always	Often	Sometimes	Never
	Always	Often	Sometimes	Never
	Always	Often	Sometimes	Never
	Always	Often	Sometimes	Never
3. My child's health care provider uses helpful ways to communicate (e.g., explaining terms clearly, helping us prepare for visits or encouraging our questions): a) With me b) With my child (If (b) does not apply to your child, check here <input type="checkbox"/> )	Always	Often	Sometimes	Never
	Always	Often	Sometimes	Never
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	

<b>Organizational Capacity of the Practice (Cont'd)</b>				
5. Office providers or staff who are involved with my child's care know about my child's 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 am aware that 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 child's health care provider and the staff at his/her office have a commitment to provide the quality care and family supports that we need.	Yes	No		
<b>Chronic Condition Management</b>				
9. My child's health care provider listens to my concerns and questions.	Always	Often	Sometimes	Never
10. My child's health care provider has asked me 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.).	Always	Often	Sometimes	Never
11. When or if I ask for it, my child's health care provider or office staff help me to:				
a) Explain my child's needs to other health professionals.	Always	Often	Sometimes	Never
b) Get my child's school, care providers or others to understand his/her condition (If (b) does not apply to your child, check here <input type="checkbox"/> )	Always	Often	Sometimes	Never
12. My child's health care provider 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		
13. My child's health care provider 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 child's health care provider 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		

### Chronic Condition Management (Cont'd)

<p>15. During the last year, the number of visits that my child made to the practice of his/her health care provider was: _____times</p>	
<p>16. During the last year, the number of times that my child was seen by a specialist was: _____times</p>	
<p>17. During the last year, the number of times that my child required care in the emergency room was: _____times</p>	
<p>18. During the last year, the number of <u>separate times</u> that my child had to stay in the hospital overnight was: _____times</p>	
<p>19. During the last year, the total number of nights that my child spent in the hospital was: _____nights</p>	
<p>20. <u>In the last 6 months of the school year</u>, the number of days that my child has been absent from school because of his/her chronic health condition(s) or disability was: _____days</p>	
<p>21. Is this typical (as described in #20) for school absences during the past full year of school?</p> <p><input type="checkbox"/> No, the past year has been <u>worse than</u> the past 6 months</p> <p><input type="checkbox"/> Yes, the past year has been <u>about the same</u> as the past 6 months</p> <p><input type="checkbox"/> No, the past year has been <u>better than</u> the past 6 months</p>	

### Chronic Condition Management (Cont'd)

22. In the last 6 months, the number of days that I or anyone in my family had to stay home because of my child's chronic health condition(s) or disability was:

\_\_\_\_\_ days

23. Is this typical (as described in #22) for missed work during the past full year of school?

- No, the past year has been worse than the past 6 months
- Yes, the past year has been about the same as the past 6 months
- No, the past year has been better than the past 6 months
- No one is employed

24. My regular out of pocket health expenses to care for my child's health condition or disability (excluding insurance deductibles or co-payments) are:

- None
- \$1—\$250 per year (up to about \$21/month)
- \$251—\$500 per year (up to about \$42/month)
- \$501—\$1000 per year (up to about \$83/month)
- \$1001—\$5000 per year (up to about \$417/month)
- More than \$5000 per year (more than \$417/month)

25. My out of pocket expenses are related mostly to : (Check all that apply)

- Equipment
- Supplies
- Medications
- Family support
- Counseling
- Respite care
- Other \_\_\_\_\_

Care Coordination				
26. Office staff help me to connect with (please answer a and b): a) Family support organizations and informational resources in our community and state. b) Other parents with similar concerns.	Yes Yes		No No	
27. My child's health care provider 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).	Always	Often	Sometimes	Never
28. 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) Follow-up with plans created.	Always Always Always Always	Often Often Often Often	Somewhat Somewhat Somewhat Somewhat	Never Never Never Never
29. My child's health care provider and staff have worked with our family to create a written care plan for my child. (If your answer is "never", then skip to Question 32.)	Always	Often	Somewhat	Never
30. I have received a copy of my child's care plan.	Always	Often	Sometimes	Never
31. My child's health care provider 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.	Always Always Always	Often Often Often	Sometimes Sometimes Sometimes	Never Never Never
32. My child's health care provider 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 therapy need. d) Help each person involved in my child's care to communicate with each other (with my consent).	Always Always Always Always	Often Often Often Often	Sometimes Sometimes Sometimes Sometimes	Never Never Never Never

<b>Care Coordination (Cont'd)</b>					
33. The level of satisfaction I have with the care coordination that I receive for my child from <u>outside of the family</u> is: <ul style="list-style-type: none"> <li><input type="checkbox"/> Very satisfied</li> <li><input type="checkbox"/> Somewhat satisfied</li> <li><input type="checkbox"/> Dissatisfied</li> <li><input type="checkbox"/> Very dissatisfied</li> <li><input type="checkbox"/> NA (not applicable)</li> </ul>					
<b>Community Outreach</b>					
34. My child's health care provider is a strong advocate for the rights and services important to children with special health care needs and their families.		Yes	No		
35. My child's health care provider and office staff attend events or conferences to talk about concerns and needs common to all children with special health care needs (CSHCN) and their families.		Yes	No		
<b>Cultural Competence</b>					
36. My health care provider is sensitive to my family's cultural background and beliefs about health.		Always	Often	Sometimes	Never
<b>Quality Improvement</b>					
37. I am aware that the practice is working with families to improve the quality of care for children with special health care needs (e.g.: practice improvement ideas, office changes that address needs and gaps, etc.).		Yes	No		

**COMMENTS**

38. The care and compassion that I expect from my child's health care provider would best be shown by the following behaviors: **(Write in here:)** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

39. The frequency that I observe and experience the behaviors listed above (in #38) in my child's health care provider is?

Always

Often

Sometimes

Never

**Please answer the following questions about the child with special health care needs:**

40. Name of the practice where my child with special health care needs goes for health care:

Practice Name: \_\_\_\_\_

41. Name of my child's health care provider or the health care provider who most often sees my child at the above practice?

Health care provider's name: \_\_\_\_\_

42. Number of years my child has been cared for by this practice?

Years: \_\_\_\_\_

43. My child's primary diagnosis is:

Diagnosis: \_\_\_\_\_

44. Other illnesses or chronic medical problems my child has:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

45. My child's age:

\_\_\_\_\_ years old

46. My child's sex:

- Male  
 Female

47. My child's racial/ethnic background:

- White  
 African American / black  
 Hispanic  
 Asian  
 Other (specify \_\_\_\_\_)

48. My child's health insurance status:

- No, child does not have health insurance  
 Yes, child does have health insurance

49. My child's benefits from Medicaid/All Kids/KidCare:

- No, does not receive benefits from Medicaid/  
All Kids/KidCare  
 Yes, does receive benefits from Medicaid/  
All Kids/KidCare

## FAMILY INFORMATION

50. My relationship to the child with special health care needs is:

- Mother  
 Father  
 Other (specify \_\_\_\_\_)

51. The child with special health care needs lives in the same home as me:

- Yes  
 No

52. The number of other children who live in my home:

- One  
 Two  
 Three  
 Four  
 Five  
 Six or more

53. My own employment status is:

- Full-time homemaker  
 Part-time employed  
 Full-time employed  
 Not working, but looking for work  
 Non-salaried volunteer  
 Retired  
 Unable to work due to my own disability

54. If the child has more than one parent or adult taking responsibility for him or her, what is the second adult's employment status?

- Full-time homemaker  
 Part-time employed  
 Full-time employed  
 Not working, but looking for work  
 Non-salaried volunteer  
 Retired  
 Unable to work due to his/her own disability  
 Not applicable - single-parent home

55. My own health insurance status (not my child's):

- No, I do not have health insurance for myself  
 Yes, I do have health insurance for myself

56. Estimate of my total family income (before taxes):

- over \$100,000  
 \$50,000 to \$99,999  
 \$25,000 to \$49,999  
 \$10,000 to \$24,999  
 less than \$9,999  
 Prefer not to respond

57. Is supplemental security income received to help support my child? (SSI Support)

- No, do not receive SSI Support  
 Yes, do receive SSI Support

58. Is other assistance received from the state (e.g. special medical services)?

- No  
 Yes

