

Family/Caregiver Survey

Today's date: __/__/__ (1) __Boy (2) __Girl Child's date of birth (or age in months) _____

Each of the following questions (unless otherwise stated) refers to **right now** or in the last 12 months:

1. What is your child's (most) primary medical condition? (**Circle only one**)

1) Asthma	4) Cerebral palsy
2) Attention deficit/hyperactivity disorder	5) Diabetes
3) Autism/pervasive development disorder	6) Seizure disorder/Epilepsy
	7) Other _____

2. 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

3. Does your child's medical, behavioral or other health condition affect his/her ability to do things:

1) A great deal	(3) Very little
2) Some	(4) Don't know

4. 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	

5. 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	(4) Most of the time
(2) A little of the time	(5) All of the time
(3) Some of the time	(6) NA (not applicable)

6. 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

7. 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

8. 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

9. 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	3) Sometimes
2) Often	4) Never

10. 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 (4) Most of the time
 (2) A little of the time (5) All of the time
 (3) Some of the time

11. 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

12. 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

13. 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)
 13a. Also indicate

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

14. 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 (4) 16 or more work days
 (2) 1 – 5 work days (5) No one is employed
 (3) 6 – 15 work days

15. 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

Please rate the office where your child receives care - for how they provide each of the following qualities?

*Not applicable=NA

Please circle one number on each line:	Excellent	Very Good	Good	Fair	Poor	NA*
16. Satisfaction with the overall quality of care that you receive from this office	1	2	3	4	5	NA
17. Getting an appointment when your child needs to be seen?	1	2	3	4	5	NA
18. Clear directions for who to contact or where to go for assistance when your child <u>is ill</u> .	1	2	3	4	5	NA
19. Clear directions for who to contact or where to go for assistance when your child is <u>not ill</u> .	1	2	3	4	5	NA
20. When it comes to communicating with other professionals about your child's care, this office does a(n) _____ job.	1	2	3	4	5	NA

Describe your experiences at the primary care office where your child is seen:

21. The primary care provider(s) and his/her staff work with our family to create a written care plan for my child. (If your answer is “never”, then skip to Question #23)	Never	Sometimes	Often	Always
22. I receive a copy of my child’s care plan with all updates and changes.	Never	Sometimes	Often	Always
23. My PCP (primary care provider) has a staff person(s) <u>or</u> 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
24. Office providers/staff who are involved with my child’s care know about his/her condition, history, and our concerns and priorities.	Yes		No	
25. Office staff help me to connect with family support organizations and informational resources in our community and state.	Yes		No	
26. My primary 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 _____).	Yes		No	

Comments: Please use the remaining space 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 3, 6, 7, 11, 12, 13 & 13a are from the National Survey of Children with Special Health Care Needs)