Family/Caregiver Survey

Today's date

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

- Not at all difficult
- A little difficult
- Some what difficult
- Very difficult

2. Does your child's medical, behavioral or other health condition affect his/her ability to do things: *Please choose one*

- A great deal
- Some
- Very little
- Do not know

3. During the last 3 months, how often have you worried about your child's health? *Please choose one.*

- None of the time
- A little of the time
- Some of the time
- Most of the time
- All of the time

4. 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? *Please choose one.*

- None of the time
- A little of the time
- Some of the time
- Most of the time
- All of the time
- NA (not applicable)

5. 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*

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

- Always
- Often
- Sometimes
- Never

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7. 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?

Please choose one.

Yes   No   Don't know

8. 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? *Please choose one.*

Write in the number of days ____________ (*a typical school year has 185 days)*

8a. Also indicate *Please choose one.*

None (no days absent)   Home schooled

Did not go to school   Do not know

9. 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? *Please choose one.*

None   16 or more work days

1–5 work days   No one is employed

6–15 work days

Please rate the office where your child receives care – for how they provide each of the following qualities?
Please choose one option on each line.

10. Satisfaction with the overall quality of care that you receive from this office.

Excellent   Very good   Good   Fair   Poor   Not applicable

11. Getting an appointment when your child needs to be seen?

Excellent   Very good   Good   Fair   Poor   Not applicable

12. Clear directions for who to contact or where to go for assistance when your child is ill.

Excellent   Very good   Good   Fair   Poor   Not applicable

13. When it comes to communicating with other professionals about your child's care, this office does a(n) _______________ job.

Excellent   Very good   Good   Fair   Poor   Not applicable

Please describe your experiences at the primary care office where your child is seen. *Please choose one:*

14. The primary care provider(s) and his/her staff work with our family to create a written care plan for my child.

Never   Sometimes   Often   Always

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15. My PCP (primary care provider) 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/permission).

Never Sometimes Often Always

16. Office providers/staff who are involved with my child's care know about his/her condition, history, and our concerns and priorities.

Yes No

17. Office staff helped me to connect with family support organizations and informational resources in our community and state.

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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