

Boston Children's Hospital
Pediatric Integrated Care Survey
For Parents/Guardians
SUPPLEMENTARY QUESTIONS
Version 1.0



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TOPIC 1: ADAPTING TO CHANGES

1. In the past 12 months, how often have your child's care team members modified your child's care based on changes in your child's condition or health? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- My child did not have any changes in his/her condition or health

2. In the past 12 months, how often have your child's care team members worked with you and your family to adapt to modifications in your child's care?(*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- There were no modifications in my child's care

3. In the past 12 months, how often has someone on your child's care team worked with you to plan for your child's health care when there have been big changes in your child's life? (Examples: child enters daycare, begins or finishes school, a new sibling is born, family moves) (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- There were no big changes in my child's life

TOPIC 2A: CONNECTION TO RESOURCES (GENERAL)

4. In the past 12 months, how often has someone on your child's care team given you resources you needed so that your family could be more independent in caring for your child? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- I did not need any resources to be able to care more independently for my child

5. In the past 12 months, how often did your child's care team members support you in getting additional resources that your child needed? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- My child did not need additional resources

6. In the past 12 months, how often have your child's care team members helped you to get more services at home to take care of your child's health if you needed them? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- My child did not need more services at home

**TOPIC 2B: CONNECTION TO RESOURCES
(SCHOOL, COMMUNITY AND STATE)**

7. In the past 12 months, how often did you feel that someone on your child's care team gave you enough information about schools or child care centers? *(Check ONE box)*
- Never
 - Rarely
 - Sometimes
 - Usually
 - Almost Always
 - Always
 - I did not want or need information about schools or child care centers
8. In the past 12 months, how often did you feel that someone on your child's care team gave you enough information about state or community organizations, such as Early Intervention, Head Start, Family to Family Support, Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI)? *(Check ONE box)*
- Never
 - Rarely
 - Sometimes
 - Usually
 - Almost Always
 - Always
 - I did not need information about state or community organizations
9. In the past 12 months, how often have your child's care team members made sure that you understood ways to help pay for things that insurance doesn't cover? *(Check ONE box)*
- Never
 - Rarely
 - Sometimes
 - Usually
 - Almost Always
 - Always
 - Insurance covers all costs for my child's care

10. In the past 12 months, how often have your child's care team members helped you make contact with community services when you needed them (for example, special education, recreation, after-school programs, family support services, respite care)? *(Check ONE box)*
- Never
 - Rarely
 - Sometimes
 - Usually
 - Almost Always
 - Always
 - I did not need community resources

TOPIC 3: ENHANCING COMMUNICATION

11. In the past 12 months, how often did you feel that your child's care team members talked to each other in person, by phone or by email when you thought that direct communication between them was important for your child's care? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- I don't know

12. In the past 12 months, how often have you had to repeat information about important events in your child's life or important details about your child's health that you thought care team members should have known? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always

13. In the past 12 months, did your child's care team members have any team meetings that team members attended either in person or over the phone? (*Check ONE box*)

- Yes
- No, but I would have liked this to happen
- No, but I don't think these team meeting are necessary for my child's care

14. In the past 12 months, how often have your child's care team members changed care instructions so that it would be easier for you to follow them? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- It was not necessary to change care instructions

15. In the past 12 months, how often have your child's care team members found different ways to explain things about your child's medical care to you (such as drawing a picture, showing you a video) if you did not understand their words because they were too technical or because of language barriers? (*Check ONE box*)

- Never
- Rarely
- Sometimes
- Usually
- Almost Always
- Always
- This was not necessary

