



YOUR VOICE COUNTS!!

The Health Care Experiences of Families of Children with Special Health Care Needs

A survey conducted by

Family♥Voices and Heller School, Brandeis University

The Family Partners Project

1998

..... A national survey of over 6,000 families in 20 states

..... Results will be shared with you and will be used to promote positive practices in health care, especially for children with special health care needs

..... And you're part of it! Thank you so much!

Any questions? Please call 1-800-784-6938 for answers.



Who should answer this survey?

...the birth or adoptive parent of a child with special health care needs whose child lives at home and is under age 18 years. By special health care needs, we mean a child who:

- Has a health or medical problem that is expected to last for at least one year;
- Needs frequent medications, or special diets, or medical technology, or assistive devices, or occupational, physical or speech therapy, or personal assistance;
- Needs care from physicians or mental health or other health professionals over and above what is usual for a child of the same age.

*If this **describes** you and your child... Please complete this survey. We really need and value your participation.*

*If you have more than one child who has special health needs, please fill out this survey with respect to your child with the **greatest** medical needs.*

*If this **does not describe** you... We sent this survey to you by mistake, and we apologize for your inconvenience. Please return the survey to us in the enclosed envelope so that we do not send you survey reminders. Thanks.*

Instructions ...

- The survey will take about 30 minutes to complete.
- Remember that all questions that ask about “your child” refer to your child with special health care needs.
- Use a pencil so you can change an answer if you want.
- Look over the survey before you send it back to us to make sure you didn’t skip any questions accidentally.
- Answer most questions by checking on a line or in a box. For other questions, please **clearly print your answer**, as long or as short as you want.

All your answers will be kept completely confidential. Nothing you tell us will affect any services or benefits for your child.

Thank you very much for participating in this survey!



Please tell us about your child with the greatest medical needs...

1. What is your child's birth date (month, day, and year)?

____ / ____ / ____
(month) (day) (year)

2. Is your child male or female?

____ (1) Male

____ (2) Female

3. Which of the following categories best describes the race or ethnicity of your child?

____ (1) White or Caucasian

____ (2) Black or African American

____ (3) Asian, Pacific Islander, or Southeast Asian

____ (4) Hispanic, Latino/Latina, or Spanish

____ (5) Native American, American Indian, Aleut, or Eskimo

____ (6) Multiracial

____ (7) Other (Please specify _____)

4. What is today's date?

____ / ____ / ____
(month) (day) (year)



9. Does your child have any of the following conditions? Please read the list carefully and check all that apply.

- | | |
|---|--|
| <input type="checkbox"/> (01) Allergies or sinus trouble | <input type="checkbox"/> (27) Orthopedic or bone problems |
| <input type="checkbox"/> (02) Asthma | <input type="checkbox"/> (28) Paraplegia/quadruplegia |
| <input type="checkbox"/> (03) Autism | <input type="checkbox"/> (29) Respiratory distress syndrome |
| <input type="checkbox"/> (04) Behavior problems | <input type="checkbox"/> (30) Scoliosis |
| <input type="checkbox"/> (05) Blood disorder (such as sickle cell anemia or hemophilia) | <input type="checkbox"/> (31) Seizure disorder |
| <input type="checkbox"/> (06) Cancer or leukemia | <input type="checkbox"/> (32) Hearing impairment |
| <input type="checkbox"/> (07) Cerebral palsy or other neuromuscular condition | <input type="checkbox"/> (33) Vision impairment |
| <input type="checkbox"/> (08) Chronic immune condition | <input type="checkbox"/> (34) Spina bifida /meningomyelocele |
| <input type="checkbox"/> (09) Chronic lung, or breathing trouble (such as BPD but not including asthma) | <input type="checkbox"/> (35) Technology dependent or assisted (Some examples are central venous line, colostomy, dialysis, feeding tube, shunts, tracheostomy, ventilator and others) |
| <input type="checkbox"/> (10) Chronic rheumatic disease | <input type="checkbox"/> (36) Other |
| <input type="checkbox"/> (11) Cleft lip and/or palate | |
| <input type="checkbox"/> (12) Congenital disorder | Please describe here any other medical conditions that affect your child. |
| <input type="checkbox"/> (13) Congenital heart disease | _____ |
| <input type="checkbox"/> (14) Cystic fibrosis | _____ |
| <input type="checkbox"/> (15) Degenerative neurological disease | _____ |
| <input type="checkbox"/> (16) Developmental delay | _____ |
| <input type="checkbox"/> (17) Diabetes | _____ |
| <input type="checkbox"/> (18) Digestive or gastrointestinal disorder | _____ |
| <input type="checkbox"/> (19) Down syndrome | _____ |
| <input type="checkbox"/> (20) Epilepsy | _____ |
| <input type="checkbox"/> (21) Head injury complications | _____ |
| <input type="checkbox"/> (22) Hydrocephalus | _____ |
| <input type="checkbox"/> (23) Kidney disease or renal failure | _____ |
| <input type="checkbox"/> (24) Mental health problems | _____ |
| <input type="checkbox"/> (25) Mental retardation | |
| <input type="checkbox"/> (26) Muscular dystrophy | |



Please tell us how your child's medical care is paid for ...

10. Does your child have a health insurance plan, that is, a health plan, health insurance, or Medicaid to help pay for the costs of medical care?

Medicaid uses special names in some states: Arizona Health Care Cost Containment in Arizona, MassHealth in Massachusetts, Medi-Cal in California, Oregon Health Plan in Oregon, TennCare in Tennessee, and Medical Assistance in District of Columbia, Maryland, Minnesota, Washington, and Wisconsin.

_____ (1) Yes (→ Go to question 12 below the box)

_____ (2) No (→ Go to question 11 in the box)

If your child has no health insurance plan...

11. What are the main reasons? Please check **all that apply**.

_____ (1) Coverage is too expensive

_____ (2) Employer does not offer health coverage

_____ (3) Health insurance plan through work does not include children or dependents

_____ (4) My spouse and I are not eligible for a health insurance plan through work

_____ (5) My child was refused coverage

_____ (6) My child used up all benefits

_____ (7) My child doesn't qualify for Medicaid

_____ (8) Other reasons (Please describe) _____

→ Go to question 32 on page 13.

12. Was your child ever without a health insurance plan at any time in the last 12 months?

_____ (1) Yes

_____ (2) No

_____ (3) Can't remember/Don't know



Thinking about your child's main health insurance plan...

13. What is the name of your child's main health insurance plan? (Your child may have more than one source of health coverage. Please tell us here the name of the plan you rely on most.)

14. How long has your child been enrolled in this health insurance plan?

- _____ (1) Less than 1 year
- _____ (2) At least 1 year but less than 2 years
- _____ (3) At least 2 years but less than 5 years
- _____ (4) Five or more years

15. How is your child's main health insurance plan paid for?

- _____ (1) Paid fully by an employer
- _____ (2) Paid partly by an employer and paid partly by the family
- _____ (3) Paid fully by the family
- _____ (4) Medicaid, Medical Assistance, TennCare, MassHealth, Arizona Health Care Cost Containment, Medi-Cal, or Oregon Health Plan
- _____ (5) Indian Health Service
- _____ (6) Other government-sponsored programs (high risk pools, state subsidy programs, CHAMPUS, etc.)
- _____ (7) Other (Please describe _____)
- _____ (8) Don't know/Not sure

16. Did you have more than one health insurance plan from which to choose when you enrolled your child in this one?

- _____ (1) Yes
- _____ (2) No
- _____ (3) Don't know/Not sure/Don't remember

17. Does your child's health insurance plan have a list or network of doctors and other providers whose care it pays for?

- _____ (1) Yes
- _____ (2) No
- _____ (3) Don't know/Not sure



18. Does this health insurance plan pay for any of the costs of your child's visits to providers who are not within its network or list of providers?

- _____ (1) Yes
- _____ (2) No
- _____ (3) Don't know/Not sure
- _____ (4) Does not apply -- the health insurance plan does not have a network or list

19. Is this health insurance plan a managed care plan?

- _____ (1) Yes
- _____ (2) No
- _____ (3) Don't know/Not sure

20. What type of health insurance plan is it? With all the changes in the health care system, we know that it is hard to answer this question. Some families know the type of health insurance plan, but many do not. Please answer this question as well as you can.

- _____ (1) HMO or IPA – In these plans, people must choose their doctors, hospitals and other health care services from the plan's provider list in order to be covered for services.
- _____ (2) POS – These plans are sometimes called "open HMOs." People are able to get services from doctors who are not part of the plan's network, but must pay a much higher price.
- _____ (3) Fee-for-service – These are traditional health insurance plans that permit you to see any provider you choose. A doctor charges a fee for each service provided. These plans often pay part of the bill, and families pay the rest.
- _____ (4) PPO – A PPO is a cross between an HMO and a fee-for-service plan. It pays for health care services using providers who are in its network and will pay some of the bill for regular care by providers who are outside the network.
- _____ (5) Another type of plan (Please describe)

- _____ (6) Don't know/Not sure



21. How is your child's main health insurance plan doing on...	Excellent	Good	Okay	Poor	Don't know
	(1)	(2)	(3)	(4)	(9)
a. Offering benefits that meet my child's needs					
b. Providing skilled and experienced primary care providers (A primary care provider is a doctor, nurse, or physician's assistant, who provides your child's ongoing medical and well-child care.)					
c. Providing skilled and experienced specialty doctors (A specialty doctor, like a surgeon, heart doctor, psychiatrist, allergy doctor, etc., specializes in one area of health care.)					
d. Providing skilled and experienced other specialists such as PTs, OTs, and speech therapists, etc.					
e. Providing access to quality hospitals					
f. Charging reasonable out-of-pocket costs for deductibles, co-payments, and coinsurance					
g. Paying for second opinions					
h. Paying for services, equipment, or providers that are outside the plan's network					
i. Making it easy for me to complete paperwork					
j. Approving emergency care					
k. Approving specialty care					
l. Providing clear information about what services are covered					
m. Providing clear information about how to get covered services					
n. Providing clear information about other services or resources outside the health insurance plan which my child or family may find useful					
o. Providing clear information about how to file a complaint					
p. Providing information or newsletters about issues of interest to families with children with special health care needs					
q. Giving families chances to advise the health insurance plan (advisory committees, focus groups, etc.)					
r. Offering parent support groups					



Please tell us about problems with your child's main health insurance plan...

22. In the last twelve months, have you **called or written** your child's main health insurance plan with a **complaint or problem**?

- _____ (1) No
- _____ (2) Yes, but not yet resolved
- _____ (3) Yes, resolved to my satisfaction
- _____ (4) Yes, resolved but **not** to my satisfaction
- _____ (5) Don't know/Not sure

23. In the last twelve months, did you ask your child's main health insurance plan to pay for a service or treatment that is not part of the benefits package (often referred to as an **exception to policy**)?

- _____ (1) No
- _____ (2) Yes, but not yet resolved
- _____ (3) Yes, resolved to my satisfaction
- _____ (4) Yes, resolved but **not** to my satisfaction
- _____ (5) Don't know/Not sure

24. In the last twelve months, did you file a formal **grievance or appeal** with your child's health insurance plan?

- _____ (1) No
- _____ (2) Yes, but not yet resolved
- _____ (3) Yes, resolved to my satisfaction
- _____ (4) Yes, resolved but **not** to my satisfaction
- _____ (5) Don't know/Not sure

25. Please tell us more about any of the above.



Please tell us how satisfied you are with your child's main health insurance plan...

26. All things considered, how satisfied are you with this main health insurance plan for your child?

- _____ (1) Very satisfied
- _____ (2) Somewhat satisfied
- _____ (3) Somewhat dissatisfied
- _____ (4) Very dissatisfied

27. Would you recommend your child's main health insurance plan to family or friends if they had a child with special health care needs?

- _____ (1) Definitely yes
- _____ (2) Probably yes
- _____ (3) Probably not
- _____ (4) Definitely not

28. If you had a chance to switch your child's main health insurance plan, would you change?

- _____ (1) Definitely not
- _____ (2) Probably not
- _____ (3) Probably yes
- _____ (4) Definitely yes

Please tell us more about your satisfaction with your child's main health plan.



Please tell us about any other health insurance plan your child has...

29. Does your child have any other health insurance plan?

- _____ (1) No (→ Go to question 32 on page 13)
- _____ (2) Yes – A private plan paid through an employer or by our family
- _____ (3) Yes – A public plan like Medicaid, a Medicaid waiver, Indian Health Service, or other government-sponsored program
- _____ (4) Don't know/Not sure (→ Go to question 32 on page 13)
- _____ (5) Other (Please describe _____)

30. For which of your child's services does this other health insurance plan pay? Please check all that apply.

- _____ (01) Premiums, co-payments, or deductibles (for your child's main health insurance plan)
- _____ (02) Therapy services, such as PT, OT, speech, or other therapies
- _____ (03) Durable medical equipment, such as ventilator, communication devices, wheelchairs, braces, etc.
- _____ (04) Disposable medical supplies, such as gloves, swabs, diapers, etc.
- _____ (05) Inpatient hospital care
- _____ (06) Outpatient care
- _____ (07) Prescription medications
- _____ (08) Transportation
- _____ (09) Case management
- _____ (10) Home health care, such as nursing care, home health aide, personal care attendants, etc.
- _____ (11) Other (please describe) _____

31. Please tell us how your child's main health insurance plan and second plan "coordinate benefits" to pay for your child's care.



Please tell us about your child's medical care...

32. Does your child have a primary care provider, that is, a doctor, nurse, or physician's assistant, who provides your child's ongoing medical and well-child care?

- _____ (1) Yes, required by my child's health insurance plan
- _____ (2) Yes, but **not** required by my child's health insurance plan
- _____ (3) No (→ Go to question 34 on this page.)
- _____ (4) Don't know/not sure (→ Go to question 34 on this page.)

33. Does your child's primary care provider have the skill and experience that is needed to care for your child?

- _____ (1) Yes
- _____ (2) No
- _____ (3) Don't know/Not sure

34. Does your child's health insurance plan **require** you to get a referral from a primary care provider in order to see a specialist?

- _____ (1) Yes
- _____ (2) No
- _____ (3) Don't know/Not sure/Does not apply

35. In the last 12 months...	0 times	1-2 times	3-5 times	6-8 times	More than 8 times
	(1)	(2)	(3)	(4)	(5)
a. My child saw a primary care provider...					
b. My child saw one or more specialists as an outpatient...					
c. My child was treated in the Emergency Room...					
d. My child was hospitalized for a medical or surgical problem...					
e. My child was hospitalized for a mental health condition...					

In the last 12 months...	0 days, no hospital stays	1-2 days	3-5 days	6-8 days	9-14 days	More than 14 days
	(1)	(2)	(3)	(4)	(5)	(6)
f. My child's longest inpatient hospital stay was ...						



Please tell us about the doctor who is most important to your child's care...

36. What kind of doctor is **most important** to your child's care now? Check only one.

- _____ (1) Primary care, general pediatrics, family practice
- _____ (2) Specialist (What kind _____)
- _____ (3) Don't know/Not sure

37. Did you choose this doctor for your child?

- _____ (1) Yes, we chose this doctor.
- _____ (2) No, we did **not** choose this doctor.
- _____ (3) Don't know/Not sure

38. How well is this doctor who is most important to your child's care doing on...	Excellent	Good	Okay	Poor	Don't know
	(1)	(2)	(3)	(4)	(9)
a. Overall, providing quality care					
b. Spending enough time with my child during a visit					
c. Keeping us waiting for a visit less than 15 minutes					
d. Explaining about my child's health needs in a way that I can understand					
e. Giving me reassurance and support					
f. Being available to give advice over the telephone					
g. Being easy to reach in an emergency					
h. Including my family in decision making and planning					
i. Giving me updated information about medical research that might help my child					
j. Showing respect for my child					
k. Respecting our culture, ethnic identity, and religious beliefs					
l. Communicating with my child's other health care providers					
m. Communicating with my child's school or early intervention program					
n. Communicating with other systems that provide services to my child (not including school)					
o. Communicating with my child's health insurance plan staff					



Please tell us about your child's medical care from specialty doctors...

39. In the last 12 months, did you have any problems getting medical care from specialty doctors that your child needed?

- _____ (1) My child did not need services from specialty doctors (→ Go to question 42 on page 16.)
- _____ (2) My child needed services from specialty doctors and we had **no problems** getting them (→ Go to question 41 on this page.)
- _____ (3) My child needed services from specialty doctors and we have had **some problems** getting them. (→ Go to question 40 in the box.)

40. If you had problems in the last 12 months getting services your child needed from specialty doctors, please check all that apply ...

- _____ (1) Getting **referrals** for services from specialty doctors was a problem.
- _____ (2) Getting **appointments** with specialty doctors was a problem.
- _____ (3) Finding specialty doctors with the **skill and experience** to care for my child was a problem.
- _____ (4) Getting the **number of visits** from specialty doctors to meet my child's needs was a problem.
- _____ (5) **Coordination** between my child's specialty doctors and other providers was a problem.
- _____ (6) The **amount we had to pay** for services from specialty doctors was a problem.
- _____ (7) My child **did not get services** from specialty doctors.
- _____ (8) The **health insurance plan would not pay** for services from specialty doctors.
- _____ (9) Other problems (Please explain _____)

→ Go to question 41.

41. In the last 12 months, who paid for your child's services from specialty doctors?
Please check all that apply.

- _____ (1) No one. My child did not get services.
- _____ (2) Main health insurance plan
- _____ (3) Second health insurance plan
- _____ (4) Our family
- _____ (5) Public program (Please specify _____)
- _____ (6) Other (Please specify _____)
- _____ (7) Don't know/Not sure



Please tell us about your child's mental health services...

42. In the last 12 months, did you have any problems getting mental health services your child needed?

- _____ (1) My child did not need mental health services (→ Go to question 45 on page 17.)
- _____ (2) My child needed mental health services and we had **no problems** getting them (→ Go to question 44 on this page.)
- _____ (3) My child needed mental health services and we have had **some problems** getting them. (→ Go to question 43 in the box.)

43. If you had problems getting mental health services your child needed, please check all that apply ...

- _____ (1) Getting **referrals** for mental health services was a problem.
- _____ (2) Getting **appointments** with mental health providers was a problem.
- _____ (3) Finding mental health providers with the **skill and experience** to care for my child was a problem.
- _____ (4) Getting the **number of visits** to meet my child's needs was a problem.
- _____ (5) **Coordination** between my child's mental health providers and other providers was a problem.
- _____ (6) The **amount we had to pay** for mental health services was a problem.
- _____ (7) My child **did not get mental health services**.
- _____ (8) The **health insurance plan would not pay** for mental health services.
- _____ (9) Other problems (Please explain _____)

→ Go to question 44.

44. In the last 12 months, who paid for your child's mental health services? Please check all that apply.

- _____ (1) No one. My child did not get services.
- _____ (2) Main health insurance plan
- _____ (3) Second health insurance plan
- _____ (4) Our family
- _____ (5) School system/Early Intervention
- _____ (6) Other public program (Please specify _____)
- _____ (7) Other (Please specify _____)
- _____ (8) Don't know/Not sure



Please tell us about your child's prescription medications...

45. In the last 12 months, did you have any problems getting prescription medications your child needed?

- _____ (1) My child did not need prescription medications. (→ Go to question 48 on page 18.)
- _____ (2) My child needed prescription medications and we had **no problems** getting them. (→ Go to question 47 on this page.)
- _____ (3) My child needed prescription medications and we have had **some problems** getting them. (→ Go to question 46 in the box.)

46. If you had problems getting prescription medications your child needed, please check all that apply ...

- _____ (1) The **drugstore or mail order service** that my child's health insurance plan uses was not convenient.
- _____ (2) Getting the **special brand** of the prescription medication that my child needs was a problem.
- _____ (3) The **frequency** with which I need to get refills was inconvenient
- _____ (4) It was **hard to get approval for new** medications used in research or clinical trials.
- _____ (5) The **amount we had to pay** for prescription medications was a problem.
- _____ (6) My child **did not get prescription medications**.
- _____ (7) The **health insurance plan would not pay** for prescription medications.
- _____ (8) Other problems (Please explain _____)

→ Go to question 47.

47. In the last 12 months, who paid for your child's prescription medications? Please check all that apply.

- _____ (1) No one. My child did not get prescription medications.
- _____ (2) Main health insurance plan
- _____ (3) Second health insurance plan
- _____ (4) Our family
- _____ (5) Public program (Please specify _____)
- _____ (6) Other (Please specify _____)
- _____ (7) Don't know/Not sure



Please tell us about your child's care from therapists...

48. In the last 12 months, did you have any problems getting the services of physical, occupational, speech or other therapists that your child needed?

- _____ (1) My child did not need any services from therapists (→ Go to question 51 on page 19.)
- _____ (2) My child needed services from therapists and we had **no problems** getting them (→ Go to question 50 on this page.)
- _____ (3) My child needed services from therapists and we have had **some problems** getting them. (→ Go to questions 49 and 50 in the boxes.)

49. If you had problems in the last 12 months getting therapy services, please check all that apply ...	P.T.	O.T.	Speech therapy	Other therapies
	(1)	(2)	(3)	(4)
a. My child did not need this therapy.				
b. My child needed but did not get this therapy.				
c. Getting a referral was a problem.				
d. Getting an appointment was a problem.				
e. Finding a therapist with the skill and experience to care for my child was a problem.				
f. Getting the number of visits to meet my child's needs was a problem.				
g. Coordination between my child's therapist and other providers was a problem.				
h. The amount we had to pay was a problem.				
i. The health insurance plan would not pay .				
j. Other problems (Please explain)				

50. Who paid for your child's therapy services? Please check all that apply.	P.T.	O.T.	Speech therapy	Other therapies
	(1)	(2)	(3)	(4)
a. No one. My child did not get this therapy				
b. Main health insurance plan				
c. Second health insurance plan				
d. Our family				
e. School system/Early Intervention				
f. Other public program				
g. Other				
h. Don't know/Not sure				



Please tell us about your child's home health care services...

51. In the last 12 months, did you have any problems getting home health care services your child needed?

Home health care services can include home nursing, help with feeding, bathing, or dressing your child, help with medical equipment, medications, and supervision.

- _____ (1) My child did not need home health care services. (→ Go to question 54 on page 20.)
- _____ (2) My child needed home health care services and we had **no problems** getting them. (→ Go to question 53 on this page.)
- _____ (3) My child needed home health care services and we have had **some problems** getting them. (→ Go to question 52 in the box.)

52. If you had problems getting home health care services your child needed, please check all that apply ...

- _____ (1) Getting a **referral** for home health care services was a problem.
- _____ (2) Finding **skilled and experienced** pediatric home health care providers to care for my child was a problem.
- _____ (3) Having **reliable** home health care providers who came when scheduled was a problem.
- _____ (4) **Coordination** between my child's home health care providers and other providers was a problem.
- _____ (5) **Getting payment** for enough home health care hours for my child's care was a problem.
- _____ (6) The **health insurance plan would not pay** for home health care services.
- _____ (7) My child **did not get** home health care services.
- _____ (8) Other problems (Please explain _____)
→ **Go to question 53.**

53. In the last 12 months, who paid for your child's home health care services? Please check all that apply.

- _____ (1) No one. My child did not get home health care services.
- _____ (2) Main health insurance plan
- _____ (3) Second health insurance plan
- _____ (4) Our family
- _____ (5) School system/Early Intervention
- _____ (6) Other public program (Please specify _____)
- _____ (7) Don't know/Not sure



Please tell us about other services your child needs...

54. In the past 12 months, did your child need...?	Yes, my child got the service and we were satisfied	Yes, my child got the service and we were dissatisfied	No, my child did not need the service	No, my child needed and did not get the service
	(1)	(2)	(3)	(4)
a. Dental care				
b. Disposable medical supplies – Such as catheters, swabs, diapers, etc.				
c. Durable medical equipment and medical technology – Such as hearing aids, wheelchairs, ventilators, etc.				
d. Genetic counseling				
e. Genetic testing				
f. Nutritional counseling				
g. Respite care				
h. Special diets or nutritional supplements				

55. Please tell us about any other services your child needs.

You're more than half way done. Please keep going!!



Please tell us about the health care you provide your child...

56. Many parents **provide** health care at home such as OT, PT, dressing changes, care of feeding or breathing equipment, etc. Do you provide this health care for your child, and if so, how much time do you usually spend **each week**?

- _____ (1) No (→ Go to question 59 on page 22)
- _____ (2) Yes, less than 4 hours each week
- _____ (3) Yes, at least 4 hours but less than 10 hours
- _____ (4) Yes, at least 10 hours but less than 20 hours
- _____ (5) Yes, 20 hours or more

57. How much time **each week** do you usually spend **arranging** or **coordinating** your child's care?

- _____ (1) None
- _____ (2) Less than 1 hour each week
- _____ (3) At least 1 hour but less than 3 hours
- _____ (4) At least 3 hours but less than 5 hours
- _____ (5) 5 hours or more

58. Does your child's main health insurance plan help you to provide health care or to arrange or to coordinate care? Please check all the ways that it helps.

- _____ (1) None
- _____ (2) Yes, gives me information
- _____ (3) Yes, provides support and technical assistance
- _____ (4) Yes, gives me education or training
- _____ (5) Yes, other (Please describe _____)
- _____ (6) Does not apply – my child has no health insurance plan



Please tell us how your child's care is coordinated...

59. Does your child have a written health care plan (other than an IFSP for Early Intervention) that describes his or her medical or health needs?

- _____ (1) Yes, has one
- _____ (2) Yes, has more than one
- _____ (3) No (→ Go to question 61 below.)
- _____ (4) Don't know/Not sure (→ Go to question 61 below.)

60. Do you have a copy of this plan?

- _____ (1) Yes
- _____ (2) No
- _____ (3) Don't know/Not sure

61. Does your child have a case manager?

A case manager is a person who makes sure that your child gets all the services that are needed and that these services fit together in a way that works for you. This person may have different titles such as care coordinator, etc.

- _____ (1) Yes, have one
- _____ (2) Yes, have more than one (How many?_____)
- _____ (8) No (→ Go to question 66 on page 24.)
- _____ (9) Don't know/Not sure (→ Go to question 66 on page 24.)

62. Does the case manager you rely on most have a good understanding of your child's health care needs and services?

- _____ (1) Yes
- _____ (2) No
- _____ (3) Don't know/Not sure



63. For which agency does the case manager you rely on most work?

- _____ (1) Health insurance plan
- _____ (2) Maternal and Child Health Program for Children with Special Health Care Needs (See the list on page 24 for the name of this program in your state.)
- _____ (3) Other state agency (Please specify _____)
- _____ (4) Other (Please specify _____)
- _____ (5) Don't know/Not sure

64. Does the case manager you rely on most...	Yes	No	Not needed
	(1)	(2)	(3)
a. Help coordinate your child's care among the different providers and services that help your child?			
b. Help you understand your child's health insurance plan benefits?			
c. Help you to identify and use other community based programs or services for which your child maybe eligible (for example, Early Intervention, special education, summer camps, after school programs, etc.)?			
d. Help you to get other public programs such as SSI for your child?			
e. Help you to find other ways to pay for needed services or equipment?			

65. If you want, please tell us more about how your child's services are coordinated.



Please tell us about other benefits your child receives...

66. In the last 12 months, did your child get ...	Yes	No
	(1)	(2)
a. Supplemental Security Income (SSI)		
b. Early Intervention (or EI) / Part H (now called Part C)		
c. Specialized health services in school – for example, OT, PT, speech therapy, nursing care, etc. – through special education or Section 504 of the Rehabilitation Act		
d. Services from your state’s Department of Mental Health		
e. Services from your state’s Department of Developmental Disabilities or Mental Retardation		
<p data-bbox="233 848 1143 957">f. Services from the Maternal and Child Health Program for Children with Special Health Care Needs – <i>*Please check the list for the program’s name in your state.</i></p> <p data-bbox="272 999 1130 1682"> Arizona - <i>Children's Rehabilitative Services (CRS)</i> California - <i>California Children Services (CCS)</i> Colorado - <i>Health Care Program for Children with Special Needs (HCP)</i> District of Columbia - <i>Health Services for Children with Special Needs</i> Delaware - <i>Children with Special Health Needs</i> Florida - <i>Children's Medical Services (CMS)</i> Kansas - <i>Services For Children with Special Health Care Needs (Special Health Services – SHS)</i> Massachusetts – <i>Division of Children with Special Health Care Needs, Department of Public Health Case Management Program</i> Maryland - <i>Children's Medical Services</i> Minnesota - <i>Children with Special Health Needs (MCSHN)</i> Missouri - <i>Children with Special Health Care Needs (CSHCN)</i> New Jersey - <i>Special Child Health Services (SCHS)</i> New Mexico - <i>Children's Medical Services (CMS)</i> New York - <i>Physically Handicapped Children's Program (PHCP)</i> Oregon - <i>The Child Development and Rehabilitation Center</i> Tennessee - <i>Children's Special Services (CSS)</i> Texas - <i>Chronically Ill and Disabled Children's Services (CIDC)</i> Utah - <i>Children with Special Health Care Needs (CSHCN)</i> Washington - <i>Office of Children with Special Health Care Needs (CSHCN)</i> Wisconsin - <i>Children with Special Health Care Needs (CSHCN)</i> </p> <p data-bbox="272 1724 1154 1833">→ If your child does not get services from your state’s Maternal and Child Health Program for Children with Special Health Care Needs, skip to question 68 on page 26.</p>		



67. For which of your child's services does your state's Maternal and Child Health Program for Children with Special Health Care Needs pay? Please check all that apply.

- (01) Premiums, co-payments, or deductibles (for your child's main health insurance plan)
- (02) Therapy services, such as PT, OT, speech, or other therapies
- (03) Durable medical equipment, such as ventilator, communication devices, wheelchairs, braces, etc.
- (04) Disposable medical supplies, such as gloves, swabs, diapers, etc.
- (05) Inpatient hospital care
- (06) Outpatient care
- (07) Prescription medications
- (08) Transportation
- (09) Case management
- (10) Home health care, such as nursing care, home health aide, personal care attendants, etc.
- (11) Other (Please describe _____)



Please tell us about you and your family...

We included the next few questions to make sure that we hear from families of all backgrounds. All answers will be confidential.

68. How are you related to your child with special health care needs?

- _____ (1) Mother
- _____ (2) Father
- _____ (3) Other (Please specify _____)

69. How would you rate your own health now?

- _____ (1) Excellent
- _____ (2) Very good
- _____ (3) Good
- _____ (4) Fair
- _____ (5) Poor

70. What is your birth date (month, day, and year)?

_____ / _____ / _____
(month) (day) (year)

71. What is the highest level of school you completed?

- _____ (1) Less than high school
- _____ (2) High school graduate or GED
- _____ (3) Some college but no degree, or Associates Degree
- _____ (4) Bachelor's degree
- _____ (5) Postgraduate degree

72. Including yourself and your child with special health needs, **how many** people in each age group usually live in your household? Please remember to tell us the number!

- _____ (1) **How many** children age 5 years and under
- _____ (2) **How many** children age 6 years through 12 years?
- _____ (3) **How many** children age 13 years through 17 years?
- _____ (4) **How many** adults age 18 years and over



73. Does your child have any brothers or sisters who have special health care needs?

_____ (1) Yes

_____ (2) No

74. What is your marital status now?

_____ (1) Married

_____ (2) Divorced

_____ (3) Separated

_____ (4) Widowed

_____ (5) Never married

_____ (6) Other (Please describe _____)

75. Do you agree or disagree with...	Strongly Agree	Agree	Disagree	Strongly Disagree	Does not apply
	(1)	(2)	(3)	(4)	(9)
a. My child's health conditions are causing financial problems for our family					
b. I have cut down the hours I work to care for my child					
c. I need additional income to cover my child's medical expenses					
d. I stopped working because of my child's health conditions					

76. Many families report higher costs for caring for a child with special health care needs. Extra costs include things like medical bills, transportation, parking, special foods, adaptive clothing, or other things. About how much extra did you spend out of your own pocket for the costs of caring for your child with special health care needs in the last 12 months?

_____ (1) Less than \$500

_____ (2) \$500 or more but less than \$1,000

_____ (3) \$1,000 or more but less than \$3,000

_____ (4) \$3,000 or more but less than \$5,000

_____ (5) More than \$5,000



77. Please tell us about what kind of services, equipment, etc. you pay for out of your own pocket.

78. What is your employment status now?

- _____ (1) Homemaker
- _____ (2) Employed part-time (30 hours/week or less)
- _____ (3) Employed full time (more than 30 hours/week)
- _____ (4) Unemployed
- _____ (5) Not working due to YOUR OWN disability
- _____ (6) Other (Please describe _____)

79. What was your total household income from all sources **before taxes** in 1997?

- _____ (1) Less than \$10,000
- _____ (2) \$10,000-\$19,999
- _____ (3) \$20,000-\$29,999
- _____ (4) \$30,000-\$39,999
- _____ (5) \$40,000-\$49,999
- _____ (6) \$50,000-\$59,999
- _____ (7) \$60,000-\$69,999
- _____ (8) \$70,000 or greater

80. How would you describe the community where you live?

- _____ (1) City or urban
- _____ (2) Suburban
- _____ (3) Farming or rural
- _____ (4) Other (Please describe _____)



If you want, please use this space below to share with us your thoughts about your child's insurance plan and the care that he or she receives.

81. What advice would you give to other families in choosing a health insurance plan?

82. What advice would you give your child's health insurance plan to help them better serve children with special health care needs?

83. What is the best thing that your child's health insurance plan does to help you care for your child?

84. Is there anything else that you want to tell us about your child's care and health insurance plan?

You're almost done. Just one more page!!



AND, FINALLY...

We want to send you the results of this survey. If you are interested in receiving a report, please fill out the information below. We will not share this information with anyone.

85. Your name? _____

86. Your street address? _____

87. City or town, state, and zip code? _____

CITY/TOWN

STATE

ZIPCODE

88. Telephone number _____ - _____ - _____

AREA CODE

89. Would you like your name to be _____ (1) Yes

added to the Family Voices _____ (2) No

mailing list? _____ (3) Already on list

**Please mail the completed survey
in the enclosed envelope.
The postage is already paid.**

Thank you for completing this survey!!

We acknowledge grant support from the Jack E. and Zella B. Butler Foundation of New York City, The David and Lucile Packard Foundation of California and the federal Bureau of Maternal and Child Health, Division of Children with Special Health Care Needs. We also get administrative support from twenty state Maternal and Child Health Programs for Children with Special Health Care Needs, the Federation for Children with Special Needs in Boston, MA, the Starr Center at the Heller School, Brandeis University, and Family♥Voices in New Mexico.



Family♥Voices



Family Voices is a national grassroots organization composed of families and professional friends who care for and about our children with special health care needs. Family leaders from around the nation organized Family Voices in December, 1992, to ensure that our children's health is addressed as public and private health care systems undergo change in communities, states, and the nation. Currently there are over 14,000 Family Voices members throughout the country.

Who are our children? It is estimated that at least 12.6 million children have a chronic condition of some kind – that's about 18% of all children in this country.

Who are our members? Anyone who has a child with a special health care need, or believes that families are the core of our health system, or works with our children, or loves our children can join Family Voices. There are no dues. You just sign on!

How are we organized? Ten regional coordinators support the Family Voices network of volunteer coordinators in every state; national staff that is located in four states. All of us are families who have children with chronic health conditions or disabilities. A board of directors, the majority of them parents of children with special health care needs, oversees our activities.

What do we do? We are advocates for our kids! Family Voices gathers and provides information about health care issues affecting our children so that all of us – families, health professionals, and policymakers—can be the advocates that our children deserve. We encourage and provide support to families who want to play a role in their child's health care, whether in a clinic, hospital, boardroom, agency office, or legislative hearing. We encourage partnerships between families and their child's health practitioner, policymakers, the media, and with other advocates who also care about children. The Family Voices staff provides information, policy papers, ideas, visits, and support for families who choose to have an active role on behalf of their children.

How are we funded? Family Voices receives grants from several private foundations and the federal Bureau of Maternal and Child Health. We also receive donations and put them to good use.

How can you reach us? Several ways:

Family Voices
PO Box 769
Algodones, New Mexico 87001

Phone: (505) 867-2368
FAX: (505) 867-6517

E-mail: kidshealth@familyvoices.org
Web-site: www.familyvoices.org



Participant ID #: _____