Date: _____

FAX

Health Division

Office of Management and Budget
Executive Office of the President
Washington, DC 20503

To: Deborah
Fax:

From: Cindy

Number of Pages (excluding cover):

Subject:

Voice Numbers:

Health Division (Front Office)	202/395-4922
Health & Human Services Unit	202/395-4925
Health Programs & Services Branch	202/395-4926
Health Financing Branch	202/395-4930

Fax Numbers:

Health Division (Front Office)	202/395-3910
Health Division (Room 7001)	202/395-7840
Health Division (Room 7002)	202/395-5648

HEALTH CARE FINANCING ADMINISTRATION

PLEASE CALL ME IN THE A.M. W/ QUESTIONS OR CONCERNS. I WILL BE IN OUR BALTIMORE OFFICE AFTER 8:00 ~ 410-786-3151.

ADDRESSEE:	FROM: NANCY-ANN / MELISSA
DAN MARK MILLER CYNTHIA SMITH PHONE:_____	OFFICE OF THE ADMINISTRATOR 200 INDEPENDENCE AVE., S.W. ROOM 314G WASHINGTON, DC 20201 PHONE: 202-690-6726 FAX : 202-690-6262

TOTAL PAGES:	ADDRESSEE'S FAX MACHINE NUMBER:	DATE:
	301-571-4421	

REMARKS:

PLEASE FIND ATTACHED AN EXCERPT FROM HCFA'S NEW GUIDELINES FOR 1915(b) WAIVER APPLICATIONS. THE GUIDELINES ARE TO BE USED BY STATES AS A CHECK-LIST AS THEY DEVELOP WAIVER APPLICATIONS. WHAT WE PLAN TO TALK ABOUT TOMORROW IS HOW WE INTEND TO WORK W/ STATES TO FURTHER DEVELOP AND OPERATIONALIZE THE GENERAL CATEGORIES OF THE ATTACHED FOR HCFA'S REVIEW CRITERIA FOR MANDATORY PROGRAMS INVOLVING SPECIAL NEEDS KIDS

Section F. Special Populations

States may wish to refer to the October 1998 HCFA document entitled "Key Approaches To The Use of Managed Care Systems For Persons With Special Health Care Needs" as guidance for efforts to ensure access and availability of services for persons with special needs. To a certain extent, key elements of that guide have been incorporated into this waiver application form.

State Responsibilities in Managed Care Programs Enrolling Children with Special Needs

I. State Definitions of Special Populations and Special Populations Inclusion in the Waiver

a.___ The State has a specific definition of "special populations" or "populations with special health care needs" which includes the following five populations at a minimum:

1.___ Blind/Disabled Children and Related Populations (Eligible for SSI under title XVI),
2.___ Eligible under section 1902(a)(3) of the Social Security Act,
3.___ In foster care or other out-of-home placement,
4.___ Receiving foster care or adoption assistance; or
5.___ Receiving services through a family-centered, community-based coordinated care system that receives grant funds under section 501(a)(1)(D) of title V, as is defined by the State in terms of either program participant or special health care needs.

The definition should include populations beyond those who are SSI or SSI-related, if appropriate, such as persons with serious and persistent mental illness, and should specify whether they include adults and/or children. Some examples include: Children with special needs due to physical and/ or mental illnesses, Foster care children, Homeless individuals, Individuals with serious and persistent mental illness and/or substance abuse, Children who are disabled or chronically ill with developmental or physical disability, Children with rare or life-threatening conditions; e.g., HIV, cancer, or other. Please describe.

II. The State identifies and includes children with special needs in the waiver.

a.___ There are special populations included in this waiver program. Please list the populations. The waiver program includes the following targeted groups of special needs children under 19 years of age. Check all items that apply:

1.___ Blind/Disabled Children and Related Populations (Eligible for SSI under title XVI),

2.___ Eligible under section 1902(a)(3) of the Social Security Act,
3.___ In foster care or other out-of-home placement,
4.___ Receiving foster care or adoption assistance; or
5.___ Receiving services through a family-centered, community-based coordinated care system that receives grant funds under section 501(a)(1)(D) of title V, as is defined by the State in terms of either program participant or special health care needs.
6.___ Other Special Needs Populations. Please ensure that any special populations in the waiver outside of the eligibility categories above are listed here.
   i.___ Children with special needs due to physical and/ or mental illnesses,
   ii.___ Homeless individuals,
   v.___ Individuals with serious and persistent mental illness and/or substance abuse,
   vi.___ children who are disabled or chronically ill with developmental or physical disability,
   vii.___ children with rare or life-threatening conditions; e.g., HIV, cancer, or
   viii.___ Other (please list):

b. **Excluded Populations:** The following enrollees will be excluded from participation in the waiver:
   1.___ are included under the State's definition of Special Needs Populations. Please ensure that any special populations excluded from the waiver in the eligibility categories are listed here:
      i.___ Children with special needs due to physical and/ or mental illnesses,
      ii.___ Homeless individuals,
      v.___ Individuals with serious and persistent mental illness and/or substance abuse,
      vi.___ children who are disabled or chronically ill with developmental or physical disability,
      vii.___ children with rare or life-threatening conditions; e.g., HIV, cancer, or
      viii.___ Other (please list):

III. **The State performs functions in the enrollment/disenrollment process for children with special needs.**

a.___ **Outreach:** The State conducts outreach to inform potential enrollees, providers, and other interested parties of the managed care program. Please describe the outreach process, and specify any special efforts made to reach and provide information to special populations included in the waiver program:

b.___ Enrollment selection counselors will have information and training to assist special populations and persons with special health care needs in selecting appropriate MCO/PHPs and providers based on their medical needs. Please describe.

c.___ If an enrollee does not select a plan within the given time frame, the enrollee will be auto-assigned or default assigned to a plan.

1. Potential enrollees will have____days/month(s) to choose a plan.
2. Please describe the auto-assignment process and/or algorithm. What factors are considered? Does the auto-assignment process assign persons with special health care needs to an MCO/PHP that includes their current provider or to an MCO/PHP that is capable of serving their particular needs?

d.___ The State allows otherwise mandated beneficiaries to request exemption from enrollment in an MCO/PHP. Please describe the circumstances under which an enrollee would be eligible for exemption from enrollment. In addition, please describe the exemption process:

e. **MCO/PHP Disenrollment of Enrollees:** The MCO/PHP can request to disenroll or transfer enrollment of an enrollee to another plan. If so, **it is important that reasons for reassignment are not discriminatory in any way -- including adverse change in an enrollee's health status and non-compliant behavior for individuals with mental health and substance abuse diagnoses -- against the enrollee.** Please describe the reasons for which the MCO/PHP can request reassignment of an enrollee:

IV. **The State ensures that the number of providers under the waiver is expected to stay approximately the same or increase compared to the number before the waiver.**

a.___ [Required] The State ensures that the number of providers under the waiver is expected to remain approximately the same or increase compared to the number before the implementation of the waiver. Please describe how the State will ensure that provider capacity will remain approximately the same or improve under the waiver.

b. [Required] For all provider types in the program, list in the chart below for each geographic area(s) applicable to your State, the number of providers before and after the waiver. **Please provide a definition of your geographic area,** i.e. by county, region or capitated rate area. Please complete only for the providers included in your waiver program.

For risk-comprehensive programs, please modify to reflect your State's program and complete the following chart (Note: HCFA is requesting baseline information that will be used by the Regions for contract approval and for future waiver renewals.):

[illegible]	[illegible]	[illegible]
FQHCs		
Hospitals		
Pharmacies		
Primary Care Providers (Please specify) - Family Practice - Internal Medicine - OB/GYNs - Pediatricians - Physician Extenders		
Other (please specify)		

*Please note any limitations to the data in the chart above here:

For other risk programs, please modify for your State's program and complete the following chart (Note: HCFA is requesting baseline information that will be used by the Regions for contract approval and for future waiver renewals):

[illegible]	[illegible]	[illegible]
Developmental Disabilities Providers (please specify)		
Hospitals		
Mental Health Providers (please specify)		
Pharmacies		
Substance Abuse Treatment & Rehab Providers (please specify)		
Transportation Providers (please specify)		
Vision Providers		
Other (please specify)		

*Please note any limitations to the data in the chart above here:

V. **The State has set capacity standards for specialty services.**

a.____ The State has set capacity standards for specialty services. Please explain.

b.____ The State monitors access to specialty services. Please explain how

often and how monitoring is done.

c. **Capacity Monitoring** -- Please indicate which of the following activities the State employs:

1.___ Consumer Experience Survey, including persons with special needs,

2.___ Other (Please explain):

VI. **The State has developed and implemented process to collaborate and coordinate with agencies which serve special needs clients, etc.**

a.___ The State has developed and implemented processes to collaborate and coordinate with, on an ongoing basis, agencies which serve special needs clients, advocates for special needs populations, special needs beneficiaries and their families. If checked, please briefly describe.

b. The State has programs/services in place which coordinate and offer additional resources and processes to ensure coordination of care among:

1.___ Other systems of care (Please specify, e.g. Medicare, HRSA Title V grants, Ryan White CARE Act, SAMHSA Mental Health and Substance Abuse Block Grant Funds)
2.___ State/local funding sources
3.___ Other (please describe):

VII. **The State has quality of care processes in place.**

a.___ The State has specific performance measures and performance improvement projects for their populations with special health care needs. Please identify the measures and improvement projects by population. Please list or attach the standard performance measures and performance improvement projects:

VIII. **The State makes payment methodology adjustments for each population enrolled in capitated managed care.**

If the State enrolls persons with special health care needs, please explain by population any payment methodology adjustments made by the State for each population. For example, HCFA expects states to set rates for each eligibility category (i.e., the State should set UPLs and rates separately for TANF, SSI, and Foster Care Children). Please list and describe the basis and methodology:

IX. The State has monitoring of MCOs/PHPs who enroll children with special needs in place.

a.___ The State has in place a process for ongoing monitoring of its listed special populations included in the waiver in the following areas:
1.___ Access to services (please describe):
2.___ Quality of Care (please describe):
3.___ Coordination of care (please describe):
4.___ Enrollee satisfaction (please describe):
5.___ Other (please describe):

b.___ The State has standards or efforts under way regarding a location's physical Americans with Disabilities Act (ADA) access compliance for enrollees with physical disabilities. Please briefly describe these efforts, and how often compliance is monitored.

State Requirements for MCOs/PHPs

I. The State has set general requirements for MCOs/PHPs enrolling children with special needs.

a.___ The State has required case management services the MCO/PHP shall provide for individuals with special health care needs. Please describe.

b.___ As part of its criteria for contracting with an MCO/PHP, the State assesses the MCO/PHP's skill and experience level in accommodating people with special needs.

c.___ The State requires MCOs/PHPs to either contract or create arrangements with providers who have traditionally served people with special needs, for example, Ryan White providers and agencies which provide care to homeless individuals. If checked, please describe.

d.___ The State has provisions in contracts with MCOs/PHPs which allow beneficiaries who utilize specialists frequently for their health care to be allowed to maintain these types of specialists as PCPs. If not checked, please explain.

e.___ The State collects or requires MCOs/PHPs to collect population-specific data for special populations. Please describe.

f.___ The State requires MCOs/PHPs that enroll people with special health care needs to provide special services, have unique medical necessity definitions and/or have unique service authorization policies and procedures.

1. **Please note any services marked in the table in Section A.III.d.1 that are for special needs populations only.**

2. **Please note for Section C.II.b any unique definitions of "medically necessary services" for special needs populations.**

3. **Please note for Section C.II.d any unique written policies and procedures for service authorizations for special needs populations. For example, are MCOs required to coordinate referrals and authorizations of services with the State's Title V agency for any special needs children who qualify for Title V assistance.**

g.___ **The State requires MCOs/PHPs to identify individuals with complex or serious medical conditions in the following ways:**

1.___ An initial and/or ongoing assessment of those conditions
2.___ The identification of medical procedures to address and/or monitor the conditions.
3.___ A treatment plan appropriate to those conditions that specifies an adequate number of direct access visits to specialists to accommodate implementation of the treatment plan.
4.___ Other (please describe):

II. **The State has set MCO/PHP enrollee information requirements.**

a.___ **Marketing and Enrollee Materials.** The State requires MCO/PHP marketing materials and enrollee materials to be translated into the languages listed below (if the State does not require translation of enrollee materials, please explain):

The State has chosen these languages because (check any that apply):

1.__ The languages comprise all prevalent languages in the MCO/PHP service area.
2.__ The languages comprise all languages in the MCO/PHP service area spoken by approximately ___ percent or more of the population.
3.__ Other (please explain):

b.___ **[Required]** The State will ensure that enrollee materials provided to enrollees by the State, the enrollment broker, and the MCO/PHP are clear and easily understandable.

c.___ Program information is available and understandable to non-English

speaking enrollees whose language needs are not met through the provision of translated material described above. Please describe.

d.___ [Required] Translation services are available to all enrollees, regardless of languages.

e.___ Every new enrollee will have access to a toll-free number to call for questions.

III. The State has set MCO/PHP specialist capacity standards.

a.___ The State requires particular specialist types to be included in the MCO/PHP network. Please identify these in the chart below, modifying the chart as necessary to reflect the specialists in your State's waiver. Please describe the standard if applicable, e.g. speciality to enrollee ratio. If specialists types are not involved in the MCO/PHP network, please describe how arrangements are made for enrollees to access these services (for waiver covered services only).

Addictionologist and/or Certified Addiction Counselors			
Allergist/Immunologist			
Cardiologist			
Chiropractors			
Dentist			
Dermatologist			
Emergency Medicine specialist			
Endocrinologist			
Gastroenterologist			
Hematologist			
Infectious/Parasitic Disease Specialist			
Neurologist			
Obstetrician/Gynecologist			
Oncologist			
Ophthalmologist			
Orthopedic Specialist			
Otolaryngologist			
Pediatrician			
Psychiatrist			
Pulmonologist			

Radiologist			
Surgeon (General)			
Surgeon (Specialty)			
Other mental health providers (please specify)			
Other dental providers(please specify)			
Other (please specify)			

IV. The State requires MCO/PHPs to coordinate the provision of services for special needs populations with providers or agencies.

a. Specify below any providers/agencies (which are excluded from the capitated waiver) that the State explicitly requires the MCO/PHP to coordinate health care services for special needs children with:

1.___ Mental Health Providers (please describe how the State ensures coordination exists):

2.___ Substance Abuse Providers (please describe how the State ensures coordination exists):

3.___ Local Health Departments (please describe how the State ensures coordination exists):

4.___ Transportation Providers (please describe how the State ensures coordination exists):

5.___ HCBS (1915c) Service (please describe how the State ensures coordination exists):

6.___ Developmental Disabilities (please describe how the State ensures coordination exists):

7.___ Title V Providers (please describe how the State ensures coordination exists):

8.___ Other (please describe):

V. The State has set other requirements for MCOs/PHPs.

a.___ The State specifies requirements of the MCO/PHPs for the special populations in the waiver that differ from those requirements described in previous sections and earlier in this section of the application. Please

FROM THE
OFFICE OF THE ADMINISTRATOR
HEALTH RESOURCES & SERVICES ADMINISTRATION

To: Deborah Adler

Fax #: (202) 456-[redacted]5557

Date: 4/28

Pages Sent: including cover sheet 33 (10+5)

Comments: Preliminary results — Nora Wells presented at AmCHP — are there specific questions you want me to pursue?

U.S. Department of Health & Human Services
Public Health Service
HRSA
Health Resources & Services Administration

5600 Fishers Lane, Rm. 14-05
Rockville, Md. 20857

(301) 443-2216
Fax: (301) 443-1246

FAMILY VOICES

Preliminary Information on the Family Survey: "Your Voice Counts!!" As of February 10, 1999

Background on the Family Survey

The Family Survey is a collaborative effort between Family Voices and the Heller School at Brandeis University. Beginning in March of 1998 surveys were sent out in waves to families of children with special health care needs across the nation to learn about their experiences with health care and health insurance. Surveys were mailed to families in 20 states that were selected to represent states with high managed care penetration in each of the 10 MCH regions. The states surveyed were: Arizona, California, Colorado, Delaware, Florida, Kansas, Maryland, Massachusetts, Minnesota, Missouri, New Jersey, New Mexico, New York, Oregon, Tennessee, Texas, Utah, Washington, Washington D.C and Wisconsin. Family names were randomly selected from Family Voices lists and from the CSHCN Title V programs in each participating state. The survey includes a special focus on the state of California. Abt Associates, a social policy research firm, is helping to conduct the survey in California.

Funding for the Family Survey

This project is funded through grants from the David and Lucile Packard Foundation, the California HealthCare Foundation, the Jack E. and Zella B. Butler Foundation, and The Division of Services for Children with Special Health Care Needs, Maternal and Child Health Bureau, Department of Health and Human Services.

The Family Survey's Definition of "special health care needs"

For the purpose of the survey we defined child with special health care needs as "a child who: has a health or medic 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."

Current Survey Returns

As of February 3rd Brandeis University had received a total of 2,139 returned, eligible surveys. As of January 29th, Abt Associates had received a total of 914 returned surveys from California only. Returns are still coming in to both Brandeis and Abt.

Information Gathered by the Family Survey

The Family Survey collected demographic profile information about respondent families. The survey asked familie for both quantitative and qualitative descriptions/assessments of their child's health and health care services. It collected information about the type of health coverage used by the child, length of enrollment and type of plan. Th survey gathered detailed information about family satisfaction with services, primary care providers, specialty doctors, mental health services, prescription medications, therapies, home health services, as well as information on coordination of care, health care families themselves provide to their child and other services the child receives.

For more information, please contact: Nora Wells, Family Voices National Coordinator at: nwells@fcsn.org
Marty Krauss, Brandeis University at: krauss@binah.cc.brandeis.edu

The following estimates are based on a total of 1,917 returned questionnaires and are only preliminary. Returned questionnaires are still being entered and figures may change when data entry is complete.

Preliminary Demographic profile of the respondents:

Based on the preliminary figures, slightly less than 1/3 of families reported living in rural areas, slightly less than 1 said they lived in a suburban community and slightly more than 1/3 reported living in a city/urban area. Slightly les than 1/3 of the respondents reported having a high school education or less, while 17% reported having their B.A. and 10% reported having done post graduate work. Half of the families surveyed reported their household income (before taxes) as less than $30,000, and 1/4 of respondents reported household income as $30,000-49,999. Slightly less than 3/4 of respondents reported being currently married and mothers were the vast majority of respondents. Almost 1/4 of the families reported that they had another child with special health care needs in addition to the one who was the focus of their survey responses. Over 2/3 of respondents reported that they had cut down the hours they worked to care for their child. More than half of people filling out the survey said that they had stopped working because of their child's health conditions. More than half of respondents agreed with the statement "my child's heal conditions are causing financial problems for our family."

Preliminary description of children:

Based on the preliminary figures, about one quarter of the children are minorities as follows: 9% Black, 8% Hispanic 6% Multiracial, 2% Native American and 1% Asian. As in other studies, fewer of the children we gathere information on were female. The most frequently reported health conditions were developmental delay, allergies, orthopedic problems, cerebral palsy, vision impairment, behavior problems, mental retardation, and seizure disorder Almost a fifth of the sample reported that their child was technology dependent. While over 3/4 of respondents reported their child's "overall health" was "excellent" to good" as opposed to "fair" to "poor.", when respondents were asked to assess the severity of their child's disability or special health condition on a scale of 1 (least severe) t 10 (most severe)- over a third of respondents rated their child's severity of condition or disability at the most severe end. Less than 1/7 of respondents reported that their child's severity was at the mild end, and 44% of respondents fe they would rate the severity of their child's condition between 4 and 7.

We are in the process of analyzing the data around a wide range of topics related to children's utilization of services health coverage and family satisfaction. In addition to the quantitative analysis, we have a substantial collection of qualitative responses to open ended questions which will be included in reports.

Family Survey Activities in 1999

1999 will be devoted to in-depth analysis of the data we have collected through the Family Survey . We are developing a range of dissemination strategies to put our findings to work in all the relevant communities. We plan provide information to the states in specific state reports as well as national overviews. We will put our findings int survey briefs, presentations, family newsletters, and with the researchers at Brandeis we will publish analytic pieces relevant journals.

The depth of the information we have gathered, the richness of our data set and the quality of information and insig provided by the families who returned their questionnaires give us real cause for excitement. We have already been contacted by a variety of families, interested allies, health care organizations, researchers and professionals who ar eager to see our data. We realize that there is a real need for this information and are eager ourselves to complete o analyses (which will be varied and complex as demanded by the breadth and level of detail of our data set) and to s sharing this information with Family Voices coordinators and interested others.

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)

Your Voice Counts!!

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

5. How would you rate your child's overall health at the present time?

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

6. Which best describes your child's situation?

_____ (1) My child's special health care needs are usually stable.
_____ (2) My child's special health care needs change only once in a while.
_____ (3) My child's special health care needs are changing all the time.

7. Overall, how would you rank the level of your child's disability or special health conditions? Please circle one number for your answer.

1.....2.....3.....4.....5.....6.....7.....8.....9.....10
mild moderate severe

8. In the last 12 months, how many days of school has your child missed because of his or her special health care needs?

_____ (1) My child is not in school so does not apply
_____ (2) None
_____ (3) 1 to 5 days
_____ (4) 6 to 14 days
_____ (5) 15 to 30 days
_____ (6) More than 30 days

Your Voice Counts!!

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

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

Please describe here any other medical conditions that affect your child.

_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____

Your Voice Counts!!

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

Your Voice Counts!!

21. **How is your child's main health insurance plan doing on...**	Excellent (1)	Good (2)	Okay (3)	Poor (4)	Don't know (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 (1)	Good (2)	Okay (3)	Poor (4)	Don't know (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. (1)	O.T. (2)	Speech therapy (3)	Other therapies (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. (1)	O.T. (2)	Speech therapy (3)	Other therapies (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 (1)	No (2)	Not needed (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 (1)	No (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		
f. Services from the Maternal and Child Health Program for Children with Special Health Care Needs – **Please check the list for the program's name in your state.* Arizona - *Children's Rehabilitative Services* (CRS) California - *California Children Services* (CCS) Colorado - *Health Care Program for Children with Special Needs* (HCP) District of Columbia - *Health Services for Children with Special Needs* Delaware - *Children with Special Health Needs* Florida - *Children's Medical Services* (CMS) Kansas - *Services For Children with Special Health Care Needs (Special Health Services – SHS)* Massachusetts – *Division of Children with Special Health Care Needs, Department of Public Health Case Management Program* Maryland - *Children's Medical Services* Minnesota - *Children with Special Health Needs* (MCSHN) Missouri - *Children with Special Health Care Needs* (CSHCN) New Jersey - *Special Child Health Services* (SCHS) New Mexico - *Children's Medical Services* (CMS) New York - *Physically Handicapped Children's Program* (PHCP) Oregon - *The Child Development and Rehabilitation Center* Tennessee - *Children's Special Services* (CSS) Texas - *Chronically Ill and Disabled Children's Services* (CIDC) Utah - *Children with Special Health Care Needs* (CSHCN) Washington - *Office of Children with Special Health Care Needs* (CSHCN) Wisconsin - *Children with Special Health Care Needs* (CSHCN) → 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.		

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 added to the Family Voices mailing list?

_____ (1) Yes

_____ (2) No

_____ (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