

**THE FAMILY PARTNERS PROJECT:
A NATIONAL SURVEY OF THE HEALTH CARE EXPERIENCES
OF FAMILIES OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS**

TECHNICAL REPORT #1:

THE SURVEY METHODOLOGY

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PURPOSE OF THIS REPORT

There are more than 12 million children with special health care needs in this country who are served in many different types of health plans. The Family Partners Project was designed to investigate the health care experiences of these children and their families. The project was a collaborative effort between faculty at the Heller School at Brandeis University and staff from Family Voices, a national organization of friends and families of children with special health care needs.

The Family Partners Project was conducted between 1997-2000 and included the development of a survey instrument that covered a variety of topics related to the health insurance coverage, services needed and received, problems and successes in accessing needed care, and parental ratings of satisfaction and performance of the child's health plan and services. Over 6000 families from 20 states across the country were selected to participate in the national survey and were mailed the survey instrument between 1998-1999. Preliminary findings from the data collected from participating families were reported in 2000 in a series of reports, fact sheets, and presentations to Congress and other agencies around the country. Additional analyses of the information collected are being conducted.

This document presents technical information on the methodology of the survey.

DEVELOPMENT OF THE SURVEY INSTRUMENT

Content of the survey instrument. The survey instrument was developed to obtain the following:

- (1) Demographic characteristics of the children and the responding parent
- (2) Child's health conditions and health status
- (3) Primary and secondary health plan or insurance coverage
- (4) Characteristics of the child's primary health plan or insurance coverage
- (5) Parental ratings of the performance of the child's primary health plan
- (6) Parental problems with and satisfaction with the child's primary health plan
- (7) Health services utilization, problems experienced, and payment sources
- (8) Parental ratings of the performance of the child's primary physician
- (9) Parental provision of health care at home
- (10) Receipt of case management services and roles of case managers
- (11) Other services and benefits received by the child
- (12) Parental advice to other families and to health plans

The development of the survey instrument included a comprehensive review of related surveys, including the National Health Interview Survey, Disability Supplement, and other national health and consumer satisfaction surveys. Survey instruments developed for studies by faculty at the Heller School on families of children with disabilities, and by Family Voices were also reviewed.

Project staff also consulted with staff at the Center for Survey Research at the University of Massachusetts-Boston, and with other investigators in the area who were developing national or state survey instruments for similarly-focused projects, including Paul Cleary (Harvard Medical School) and Charlie Homer (Boston's Children's Hospital) who are participating in the Consumer Assessment of Health Plans (CAHPS) project, Ann Taylor and Susan Epstein of New England SERVE, Deborah Allen of the Massachusetts Department of Public Health, Tara Shea of the Medicaid Working Group, Lisa Sofis of the Pediatric Alliance for Coordinated Care Project at Boston's Children's Hospital, and Trish Gallagher of the Center for Survey Research, University of Massachusetts-Boston.

Standardized scales measuring aspects of family impacts associated with having a child with special needs were also reviewed. Four items from the Impact on Family Scale (Stein & Reissman, 1980) were included in the survey.

Our overriding goal was to develop questions that reflected the range of experiences parents have in accessing appropriate, needed, high-quality health and related services for their children with special health care needs. We were particularly interested in including questions about "hassles" that many parents report in obtaining care in a timely fashion, of sufficient intensity, and from appropriately trained providers.

Coordination of care issues were also included in the survey instrument.

While the final version of the survey includes many standardized questions regarding child and family demographic characteristics, the questions regarding utilization of different types of health and therapeutic services, problems experienced in obtaining such services, and parental roles in providing and managing health related care were constructed by the project staff.

Review and pretesting of the survey instrument. Preliminary versions of the survey instrument were reviewed for item clarity and topic coverage by:

- health services researchers and professionals,
- national Family Voices staff,
- Family Voices State Coordinators in the 20 participating states,
- State Children with Special Health Care Needs program directors, and
- professionals from two managed care plan associations.

Extensive comments were given and appropriate revisions were incorporated into the survey instrument. A pre-test of the instrument was then conducted with a group of Family Voices State Coordinators. They completed the draft survey and provided written comments regarding the instrument, resulting in further revisions.

The revised instrument and all materials to be sent to prospective sample members (i.e., introductory letter and explanation of the study) were then pre-tested in two focus groups of a total of 18 parents of children with special health care needs convened in Florida and in New Mexico. Focus group members completed the survey independently and marked areas on the survey for which they had suggestions or concerns. After the pre-test was completed, the Family Voices State Coordinator led a discussion with the focus group members about the survey instrument. The results of the two focus groups' review were then discussed with the project staff. Final revisions were then made to the survey instrument.

Translation of the instrument into Spanish. The survey instrument was translated into Spanish by an experienced translator from Chile with a medical background. It was then back translated into English by a translator from the California Children's Services program, resulting in minor changes to the Spanish version of the survey instrument.

SAMPLING PROCEDURES

This nationwide survey of families of children with special health care needs sought families from a broad geographic area as well as from diverse socio-economic backgrounds. To achieve this, target states were first selected. Within each state, families were then identified for participation in the survey.

State sampling procedures

Twenty states were chosen for participation in this study according to their geographic location and the state's market penetration by managed care organizations. Within each of the ten federal Health and Human Services region, the two states with the highest proportion of citizens covered in managed care plans were selected for inclusion in the study. Information regarding managed care penetration in each state was obtained from the 1996 Hoechst Marion Roussel Managed Care Digest Series/HMO-PPO Digest. This procedure led to the selection of the following states:

Region:	States:
I	Massachusetts and New Hampshire
II	New Jersey and New York
III	Delaware, District of Columbia, Maryland
IV	Florida, Tennessee
V	Minnesota, Wisconsin
VI	New Mexico, Texas
VII	Kansas, Missouri
VIII	Colorado, Utah
IX	Arizona, California
X	Oregon, Washington

Family sampling procedures

Families of children with special health care needs were recruited from two sources within each state: (1) Family Voices mailing lists, and (2) the state Title V Program for Children with Special Health Care Needs. These sources of families were selected to ensure a full range of socio-demographic characteristics (economic, education, racial/ethnic, etc.) and children with a broad range of special health care needs.

Family Voices is a national, voluntary, grassroots organization whose membership numbers approximately 30,000 families. Its main purpose is to inform families and professionals about health care issues for children with special health care needs. The organization is staffed with national offices in four locations, ten regional coordinators, and volunteer coordinators in all states. In each state, volunteer coordinators develop and maintain mailing lists of families who have children with special health care needs, and professionals or other interested citizens who want to receive information from Family Voices. Inclusion on the mailing lists of Family Voices is free and available to anyone requesting inclusion.

Title V Programs for Children with Special Health Care Needs are funded through the Social Security Act under the Maternal and Child Health Block Grants to states, which have the purpose of improvement of the health of all mothers and children in the nation including children with special health care needs. Federal funds are matched by

state funds. The programs vary from state to state in eligibility criteria, services, and benefits provided.

The original sampling plan was to solicit participation in the survey from an equal number of Family Voices members and Title V participants (n=100 for both sources per state, yielding a total sample frame of 200 families per state). A grant from the federal Maternal and Child Health Bureau (the funder of Title V programs in the states) was offered to double the sample size solicited from the Title V programs in each state. Further, in order to ensure that children with the most severe health care needs were included in the survey, participating states were asked to draw their sampling pools from children who were recipients of Supplemental Security Income (SSI) benefits, when this was feasible.

From these two groups (i.e., the Family Voices lists and the Title V/SSI recipient lists), the project sought as respondents those who met the following criteria:

- the biological or adoptive parent of a child with special health care needs,
- the child lived at home, and
- the child was under age 18 years

We defined “*special health care needs*” as follows:

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

To create a sampling frame for the Family Voices component of the study, Family Voices coordinators in the states participating in the project were asked to:

- (1) Review their state mailing lists to prepare for the sample selection;
- (2) delete entries that were professionals or organizations in their state;
- (3) delete names of parents whose child with special needs is deceased (if known);
- (4) update mailing addresses, where possible.

Some Family Voices state coordinators specially enlisted new members for the project. In Oregon, Tennessee, Utah, and Washington State, the Family Voices membership was smaller than the targeted sample size (n=100), so the state coordinators gained access to alternate mailing lists of potentially eligible families. These names were added to the pool and random selection was used to supplement the original Family Voices rosters.

The finalized lists of Family Voices members for each participating state were sent to Brandeis University project offices and a computerized random sample was taken. By these mechanisms, a sample of 100-115 Family Voices or related family organizations' members was identified in each state. All mailings to families selected from the Family Voices mailing lists were personalized.

Because of the variability in Title V eligibility criteria, the project asked the programs to select for participation 200 children with more complex medical problems, specially targeting children dually enrolled in Title V and SSI when possible. Eighteen of the 20 states that participated in the survey did not release families' names to the project. Instead, numbered envelopes with non-personalized enclosures were forwarded to Title V coordinators in these states who applied address labels and forwarded the materials to families. In New York and Tennessee, the Title V programs provided the project with the names and addresses of families who indicated their willingness to participate in the survey; in these states, materials to Title V families were personalized. In Delaware, the Title V program could not identify children enrolled in SSI; instead the state's Medicaid agency coordinated the study and selected children from the SSI rolls.

Three departures from the sampling plan are noted. Project staff eliminated New Hampshire from the sampling frame because families of children with special health care needs had been surveyed quite recently (by New England SERVE). Washington State Title V families were not surveyed because the program participants had been told upon enrollment in Title V that their names would never be released or utilized for any purposes other than provision of services. The families to whom the survey was sent in the State of Washington were selected from the Family Voices mailing list. Finally, the District of Columbia was added to the sample because its Title V programs enrolls all children with special health care needs in targeted managed care plans.

DATA COLLECTION PROCEDURES

Surveys were mailed to families in four waves. The survey schedule and participating states are listed in the table below.

<p>WAVE 1: Arizona Delaware New Mexico New York Tennessee Texas</p>	<p>Surveyed March 23 – May 4, 1998</p>
<p>WAVE 2: Colorado Florida Minnesota Oregon Utah Wisconsin Tennessee (Title V second group)</p>	<p>Surveyed April 27 – June 10, 1998</p>
<p>WAVE 3: District of Columbia Kansas Massachusetts Maryland (Family Voices only) Missouri New Jersey</p>	<p>Surveyed June 15 – July 15, 1998</p>
<p>WAVE 4: Follow-up to families with updated addresses California Maryland (Title V) Oregon (Family Voices second group) Washington</p>	<p>November 5, 1998 – March 10, 1999</p>

Families were sent the following items at two-week intervals:

- (1) An introductory letter to describe the study with Questions and Answer sheets (Q&A) to address common concerns; (Families who were ineligible or uninterested in participating were encouraged to call the project's 800 (toll free) number to withdraw from the study. In five states (CO, KS, MN, OR, and WI), the Title V program added a supporting cover letter to the first mailing.)
- (2) the survey;
- (3) a reminder postcard to non-respondents; and
- (4) a second copy of the survey for continued non-respondents.

Upon receipt of a completed survey, each respondent was sent a thank you letter to acknowledge his/her contribution to the project. Some respondents enclosed additional materials with their survey instrument (such as the child's IEP, information about their health plan, copies of correspondence between the respondent and the health plan, etc.) in order to provide more detailed information to the project. These respondents were sent an individualized thank you letter that indicated we received and appreciated the additional materials sent.

RESPONSE RATES

The sample for the study included 6,477 families of whom 1,069 were classified as ineligible for one of the following reasons:

- (1) The respondent was other than the adoptive or biological parent, grandparent, or other co-residing family member of the child with special health care needs;
- (2) The child with special health care needs on whom the survey was completed was over age 18;
- (3) The child with special health care needs was deceased;
- (4) The survey was mailed to a family who had moved and for whom no forwarding address was available;
- (5) The respondent indicated he or she did not have a child with special health care needs.

Excluding the 1,069 “ineligibles” from the total number of families initially contacted (6,477) resulted in a potential sample of 5,408 from which responses were received from 2,220 respondents, yielding an overall study response rate of 41.5%. This sample includes 888 respondents drawn from the Family Voices mailing lists (44.0% response rate) and 1334 respondents from the Title V mailing lists (39.4% response rate).

The following table indicates the number of cases in the database by source of the sample and by state.

Composition of Sample by State and Source			
State	Title V	Family Voices	Total In State
Arizona	51	32	83
California	36	194	230
Colorado	77	30	107
Delaware	34	9	43
District of Columbia	76	0	76
Florida	37	26	63
Kansas	78	32	110
Maryland	43	28	71
Massachusetts	68	35	103
Minnesota	94	44	138
Missouri	79	37	116
New Jersey	73	46	119
New Mexico	58	36	94
New York	118	32	150
Oregon	66	60	126
Tennessee	48	52	100
Texas	51	34	85
Utah	60	43	103
Washington	0	114	114
Wisconsin	130	59	189
Total	1277	943	2220

CODING OF THE DATA

Every returned survey was visually inspected for completeness and prepared for data entry by trained graduate students at the Heller School, Brandeis University. Coding rules were established to resolve ambiguous or unanticipated responses (i.e., respondent chose two responses to a question for which only one response was requested). Items for which no responses were provided were coded either as missing or not applicable, as appropriate. The data were processed into non-delimited, columned ASCII text files by a commercial vendor, with double entry to ensure accuracy.

All responses to open-ended questions (including questions for which “other, please specify” was a legitimate response) were entered into word processing files by the respondent’s ID number. The ID number was constructed to identify the state and source (i.e., the Family Voices sampling frame or the Title V sampling frame) of the respondent.

DATA CLEANING AND FILE CONSTRUCTION

Careful data cleaning procedures were established to construct valid variables used in the analysis. Several areas of the survey instrument were particularly prone to inconsistent or illogical response patterns that required careful review of the individual surveys to resolve. Computer programs were written to override the original data entered into the ASCII text files based on decision rules established in the data cleaning procedures.

FOR FURTHER INFORMATION on the methodology of the survey, suggestions for revisions to the survey instrument, or results from the study, please contact:

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