What Do Families Say About Health Care for Children with Special Health Care Needs?

Your Voice Counts!!
The Family Partners Project
Report to Families

April 2000
2nd edition
More information about this study can be found on the Family Voices website: www.familyvoices.org

Acknowledgments
Support for this project was provided by the David and Lucile Packard Foundation of California, the Jack E. and Zella B. Butler Foundation of New York City and the Division of Services for Children with Special Health Care Needs, Bureau of Maternal and Child Health, Health Resources and Services Administration, U.S. Department of Health and Human Services. We also received administrative support from participating state Maternal and Child Health Programs for Children with Special Health Care Needs, the Federation for Children with Special Needs in Boston, MA, Brandeis University and Family Voices, Inc in New Mexico.

Suggested Citation for This Report:

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There are more than 12 million children with special health care needs in this country. Family Partners, a collaborative project of Family Voices and Brandeis University, began with the goal of finding out about the health care experiences of these children and their families. In 1997 we developed a survey with the help of professionals and family leaders from around the country. The survey, Your Voice Counts!!, was mailed to families in 20 states between March 1998, and April 1999, and 2,220 families responded. The families who responded so generously tell a vivid story of how their child and family are faring in the present health care system. Their answers to our questions are summarized in this report. Excerpts from their insightful comments are also included.

"...As Americans, we believe that good health care is a right, not a privilege...Raising handicapped children is difficult and we should get at least some help... We get none."

A parent responding to the survey

"...As much as I dread paperwork, I decided to complete this one in the hope that someone will benefit..."

A parent responding to the survey
**Who are the children and families?**

Children with special health care needs whose families participated in this study had a wide variety of conditions. Many of the children had several conditions and most used health care and related services frequently.

- The children ranged in age from 3 months to 18 years. More than half (58%) were boys. Over one quarter of the children were from minority backgrounds, including 10% African American, 9% Hispanic, 6% multi-racial, 2% Asian or Pacific Islander and 1.5% Native American.

- Most children had more than one health condition or disability. The most common conditions were allergies, cerebral palsy, behavioral problems, orthopedic problems, vision problems, mental retardation, seizure disorders and asthma. Slightly over one sixth of the children (17%) were technology dependent or assisted, needing such things as a feeding tube, shunt, ventilator, etc.

- One third of the children (35%) were described by their parents as having a severe health condition. Parents reported that almost half of the children were in excellent or very good health, but one quarter of school-aged children missed more than 15 days of school in the preceding year.

The children lived in families with different income levels in a variety of communities.

- Eighty eight percent of those filling out the survey were mothers. Most of the respondents (72%) were married. Slightly over half worked either full time (29%), or part-time (24%). The average annual income for families was $34,327, with 34% earning less than $20,000 and 19% earning over $60,000.

- Slightly more than one-third (37%) of the families lived in city/urban communities, 31% in suburban areas and 26% in rural areas. Almost a quarter (23%) of the families had another child with special health care needs.
What kind of health coverage do these children have?

The children had health coverage paid for by employers, families and/or government programs.

• Only 3% of the children had no health insurance at the time of the survey. However 6% had been without insurance some time during the preceding year.

• A little more than a third of the children had Medicaid as the payer of their primary health plan. Two thirds had primary health plans paid for by a parent’s employer, the family itself, or a combination of the two.

• A third of children were covered by a second health plan, usually Medicaid or another government program. Families with a second plan from a public source such as Medicaid got more care from specialty doctors, home health services, therapies, and other services.

Many children were covered by managed care plans, while other children had plans without managed care features.

• Nearly half of the families said their child was in a managed care plan. However, 33% did not know what kind of plan their child had. Over half the plans required a primary care provider (PCP) and of these plans, a majority (86%) required a referral from the PCP for specialized health services.

The children also received services from other government programs and/or school systems.

• Seventy six percent of the children 5 years or older who attended school received specialized health services in school; 70% of the children under 3 years old received early intervention.

• Almost half (44%) of the children received services from their state Maternal and Child Health Program for Children with Special Health Care Needs, 25% received Mental Retardation/Developmental Disabilities (MR/DD) services, 10% received services from the Department of Mental Health.

• More then one third of the children received SSI.

• Therapies, mental health, and home health were often paid for by a combination of payers, including schools, other public programs and health plans, as well as families themselves.
How often do these children use health care services? What kind of care do they use?

Children used primary care providers, specialists, and hospitals frequently in the 12 months prior to the survey.

- Ninety five percent of the children had seen their primary care provider at least once in the previous year. 22% had seen their primary care provider more than 8 times.

- Eighty seven percent of the children had seen a specialist at least once and 21% had seen a specialist more than eight times in the previous year.

- Forty four percent of the children in the study used emergency room services in the previous year; 14% had been in the emergency room three or more times.

- Thirty nine percent of the children had been hospitalized in the year before the survey, while 11% had been hospitalized three or more times.

Almost all of the children used specialty services in the 12 months prior to the survey.

- Ninety percent of the children used prescription medications (Meds); 82% used specialty doctors; 47% received speech therapy services, 46% physical therapy, and 45% occupational therapy; 28% received home health care; 18% received mental health services.

- In the year before the survey, almost half of the children used durable medical equipment (wheelchairs, ventilators, hearing aids etc.); over a third used disposable medical supplies (catheters, swabs, etc.); a quarter received nutritional counseling; 30% received respite services; 72% received dental care.
Many parents reported having problems getting specialty services for their children, especially mental health services and home health services, but also therapy services, specialty doctors and prescription medications. Specialty services were often paid for by a mix of health insurance and public programs.

- Of children receiving home health care, 48% had problems such as finding skilled and experienced providers; having unreliable providers; being denied payment by child's health plan; and/or getting approval for the number of hours of service needed by the child.

- Of children receiving mental health services, 43% had problems such as finding skilled and experienced providers; getting referrals; getting appointments; out-of-pocket costs; and/or not receiving the necessary number of visits.

- Of children receiving therapy services, 27% had problems getting speech therapy; 27% had problems getting physical therapy; 26% had problems getting occupational therapy. Reasons included: caps on the number of visits allowed; payment denial by child's main health plan; lack of skilled and experienced therapists; and/or difficulty getting referrals for the service.

- Of children seen by specialty doctors, 23% had problems such as getting appointments; finding specialists with necessary skills and experience; and/or being denied payment for specialty doctor visits.

- Of the children using prescription medications, 21% had problems such as the frequency of necessary refills; difficulty getting the special brand of medication needed; and/or difficulty getting approval for new medications considered "experimental" by the plan.

- Most families reported more than one payer for specialty services.

- Families also said they were dissatisfied with, or needed but did not get: respite services (46%); nutritional supplements (38%); durable medical equipment (31%); disposable medical supplies (26%); dental care (18%).

"...We have been told that our plan does not cover developmental disabilities. Specifically, they don't cover autism because "it is not curable."
HOW

are children’s services coordinated among health insurance plans, government agencies, schools?

For families who had a case manager, some case management services were helpful. Many families, however, reported not getting the care coordination they needed.

- Almost half (49%) of parents reported that their child had a case manager.
- Seventy one percent of families having a case manager reported that the case manager they “relied on most” had a “good understanding” of their child’s health care needs and services.
- Thirty percent of families reported that the child’s case manager worked for the state Maternal and Child Health Program for Children with Special Health Care Needs; 28% worked for other public or private programs, such as Early Intervention, etc. Only 11% of families received case management services from their primary health insurance plan.
- Around two thirds of families with case managers said that their care coordinator helped them identify and use community based services and coordinate care when they needed it. Only around half of the families with case managers said that their care coordinator helped them find ways to pay for needed equipment, helped them access other public programs, or helped them understand their child’s insurance benefits when they needed it.

Many parents reported that they coordinated the numerous systems and payers of health care for their children themselves, sometimes with great difficulty.

"...I make a lot of phone calls and coordinate most of it myself. It would be nice to have some qualified help."

"...I feel the concept of ‘care coordination’ is a myth. All of my son’s health care is fragmented and left to parents to “coordinate” as best we can."

"...I do it and I’m tired."
To better coordinate their child's care and identify resources, many parents found information through other parents. Families expressed frustration with care coordination systems that did not help:

"...Case managers never last; thus, families are constantly having to talk to different individuals every time they turn around. This is very uncomfortable for families."

"...Our case manager only gives me information about things I ask for. I am not informed of programs available for my daughter unless I ask about it - she then needs to get back to me because she does not know."

"...No one has ever told me about what is available really. Other parents telling parents is where I get 99.9% of information. My child would not have EPSDT, nursing care, a handicap placard, and diapers paid for if not for parents telling me."

"...The system would work well if caseworkers did not change so often; and if the state's 'managed care' personnel would listen to the caseworkers and their recommendations when making decisions; and if they would examine each request on the basis of the patient's real need through documentation, history and recommendations rather than just the cost to the system."

When care coordination worked, families found it helpful:

"...My case manager will schedule visits with doctors, communicate between them, keep track of billing. She will offer suggestions for medical and information services, and suggestions for financial help.... We are happy with her help."

"...She (the case manager) is wonderful! She provides parent network information, whole family support, and flexible funding. She attends IEP meetings as the advocate and advocates for insurance coverage."
How satisfied are parents with their child’s primary health insurance plan?

Most parents said they were somewhat or very satisfied with their child’s plan. However, they expressed less satisfaction when asked specific questions about the plan.

- Forty one percent of the families said they were very satisfied with their child’s health plan, while 42% were somewhat satisfied, 11% somewhat dissatisfied, and 5% very dissatisfied.
- When asked if their plan’s benefits met their child’s health needs, only 60% gave their plan a good or excellent rating.

Almost half of the families gave lower ratings to certain aspects of their child’s plan. For example: quality of specialists (such as therapists), getting basic information from the plan, or family centered features of the plan.

- Families gave their child’s health plan higher ratings for having skilled and experienced primary care doctors (80%) and specialty care doctors (75%) than for having skilled and experienced other providers such as therapists (54%).
- Less than half of families gave good ratings to their plan for giving clear information about what services are covered, how to use services and/or how to file complaints. Only a quarter of families gave good ratings to the plan for providing information on how to find other services outside of the plan that might help their child.
- Less than a quarter of families gave good ratings to the plan on offering support groups, including families on advisory boards, or providing family newsletters.

“...As far as medical needs are concerned, everything is great. But we get no coverage for any therapies. Our son is excluded from any benefits due to his disability.”

“...Medicaid, as long as I live in poverty, will pay the hospital bills. If I had a decent income, they would not and I couldn’t afford his many hospitalizations - a Catch 22. At least in poverty, I am home with my children - trapped by all the ‘trappings’ of poverty.”
Families whose child's primary plan was paid by Medicaid were more satisfied and described fewer problems than families in private health plans.

- The advantages of Medicaid were: the broad range of services covered under Medicaid and fewer out-of-pocket expenses.

Families were less satisfied when their plan was more “managed-” when it required approvals for specialty care or placed limits on the choice of doctors or specialists.

- Responding to a range of questions about benefits and providers, families whose child's plan had more managed care features gave the plan lower performance ratings.

Families of children with certain conditions were more dissatisfied with their child's plan.

- Families of children in poorer health were more dissatisfied with their children’s health insurance plans. Families of children with autism, mental health, and behavioral problems were the most dissatisfied with their plans.

Many families had contacted their child’s plan in the past year with a problem

- Approximately one third (37%) of parents reported they had called or written the plan in the last year with a complaint or problem; of those resolved, 42% were dissatisfied with the outcome of their complaint.

- Twenty four percent of parents reported asking for an “exception to policy” from their child's main health plan in the past year; of those resolved, 61% were dissatisfied with the outcome to the request for “exception to policy.”

- Seven percent of parents had filed a formal grievance or appeal of a decision made by their child's main health insurance plan; of this small number who filed a formal complaint, 54% (55 respondents) were not happy with the outcome of filing a formal grievance.

- “...We must constantly justify and re-justify items such as home nursing care, medical supplies and medical equipment for a child the insurance company knows is permanently disabled.”

- “...My insurance denied my child a special aid wheelchair. They said my quadriplegic child could sit and be properly supported in a standard wheelchair.”

- “...I believe my child’s main health plan is very good for a typical child with health care issues. But there’s not enough knowledge on behalf of health care officials to the real needs and issues of special needs children.”
How satisfied are parents with the primary care provider and the doctor most important to their child’s care?

Most families gave high ratings to their child’s primary care provider and to the doctor they identified as most important to their child’s care.

- Ninety two percent of families said that their child had a primary care provider, and 80% said that this primary care provider had the skill and experience their child needed.

- The doctor identified by almost half the families as “most important” to their child’s care was a specialist. The other half said that their child’s most important doctor was a primary care doctor.

- Ninety percent of parents rated their child’s most important doctor as “good” or “excellent.”

- About a third of parents gave lower ratings to their doctor when asked to rate items such as being easy to reach in an emergency and being available to give advice over the phone.

- About a third of parents gave lower ratings on items such as if the doctor communicated with their child’s school, early intervention program or with other systems that provide services to their child.

- Forty two percent gave lower ratings when asked about being given updated information on medical research that might help their child.

“…His doctor is a gem! She spends lots of time with us and knows we can’t wait in the waiting room.”

“…Our son’s primary care physician is integral to why we like our insurance plan so much. He is not miserly when referring us for additional services. We did not join our managed care plan until this physician became part of that network.”
What kind of impact does a child with special health care needs have on a family?

For many parents, having a child with special health care needs has a significant family impact, affecting their finances, jobs and time spent providing direct health care.

• Nearly two thirds of the parents reported that they had reduced their hours of employment and/or stopped working altogether because of their child’s health conditions.

• Half of the families reported experiencing financial hardship associated with meeting their child’s needs. The majority of parents incurred out of pocket expenses in meeting their child’s needs. Almost half reported spending over $1,000 in the preceding year and 10% reported spending in excess of $5,000.

• Families who had a child with Medicaid as a primary plan were less likely to report an impact on family finances.

• Over half of the mothers responding provided some health care to their child at home each week such as physical therapy, dressing changes or care of feeding or breathing equipment.

• A fifth spent 20 or more hours per week providing health care at home to their child with special needs.

“...Special health care families need to be flagged in the system of insurance companies... I have been waiting on a reimbursement of over $600 from insurance claims as old as 2 to 3 months - that's more than my house payment! If your child is ill, you miss work, causing financial difficulties, compounded by the cost of 'out of pocket' deductibles and then WAITING for reimbursement.”

“...They (health plans) need to understand that preventive medicine costs less than letting people get worse and sick. If parents can get some help taking care of their children at home, in the long run, it will cost the company less, and everyone will be better off.”
What advice do families have for other parents of children with special health care needs?

The families in our study urged parents to educate themselves about their children's health coverage and care by talking to everyone they can, especially other parents.

Parents advised careful examination of health plans. They emphasized reading everything and requesting health plans to clarify any questions.

“...Read EVERYTHING and ask questions.”

“...Be careful – read the fine print. Have someone you trust explain in your primary language. Ask questions (lots). There are good plans that have caring, competent doctors who will work for you and with you. Only learn to trust your own judgement. It’s your child. No one knows them better.”

Many emphasized the importance of talking to other families of children with special health care needs.

“...Don’t just believe what the rep tells you. They don’t always understand how or what is not covered under their own plans when it concerns people with disabilities. Speak, if possible, with other parents of children with disabilities about that plan before choosing that plan.”

“...Talk to other parents about doctors who work with children with special needs and look for a plan that has these doctors.”

Many parents gave advice about how to look at a plan, and how to choose.

“...Make a list of the health problems you have. Then make a list of what you need to take care of it. Get some help to research who can give you what you need with little or no cost.”

“...Choose a plan that offers choices and a large provider base. Know your plan well. Ask for what your child needs, even if it is not in the plan, especially if the same care will save them money in the long run.”

“...Read through the policy first! What are the ‘caps’ on spending? This isn’t always immediately clear. Watch out for ‘pre-existing’ conditions clauses. How are they about referrals to specialists (i.e., pediatric orthopedic surgeons, pediatric cardiologists)? How generous are they with mental health benefits? ”

“...Learn how to advocate for your needs. Only accept a primary care physician who knows and respects you. Learn how to appeal decisions and NEVER STOP ROCKING THE BOAT.”
What kind of advice do parents have for their child’s health plan?

Parents suggested that health plans designate a person who knows how the health plan operates, such as a case manager, to guide families who have children with special health care needs. They also suggested that plans learn more about children with special health care needs directly from families and offer more family-friendly services.

Have special services for children with special health care needs

“…Have a case manager to work with the family. The family should have a real role in developing a care plan. The plan should be developed outside of the provider, but the provider should follow the plan. A review board for complaints should exist outside of the HMO.”

“…Get knowledgeable people! So frustrating to know more about the disability than the doctors!”

“…Have clear cut policies of therapies, surgeries, medical equipment … Be conscientious about how stressful our lives are and be compassionate.”

“…We need stronger, more involved case management. We have a hotline for gambling and substance abuse, but nothing for those of us who deal with day to day (and sometimes minute to minute) airway problems.”

Offer family friendly services

“…Help set up a support group or meeting with other parents who have children with the same health care needs in order to share information and be able to take better care and make better decisions for the children.”

“…Be aware that our children have the right to the same quality of life as everyone else. That sometimes means they need some extra services and equipment and it should be covered without families having to beg for help.”

Learn about these children from their families

“…Parents know the needs of their child best. They are with them 24 hours a day, 7 days a week. We need to be comfortable with the doctors we need for our child’s care and to obtain appropriate equipment and services.”

“…Please take a ‘global view’ of the child – i.e. family situation, quality of life issues. The child’s health issues as a whole – not ‘piece management.’”

“…Tell them to walk a mile in our shoes. Make sure they have qualified medical personnel on their review board before they get too quick to judge a service as not medically necessary.”
In conclusion, what does the family survey tell us?

While some parts of the health care financing and delivery system are serving children well, other parts are not meeting their needs. Many families who have children with special health care needs struggle to navigate a complicated mix of services from health plans, public programs and private agencies.

About Public Policy

• Children with special health care needs are a small but significant part of our nation’s population of children. Though not well understood by many health plans, nevertheless their experiences are reflections of how well our health systems are performing, and should be monitored carefully.

• Medicaid is an essential program for children with special health care needs. Its benefits should serve as a model for all children needing specialized health care services, whether publicly or privately funded.

• For some children whose primary health coverage benefits are limited, secondary health care coverage, like Medicaid, is essential.

About Health Plans

• Children with special health care needs require flexibility in health care plans such as streamlined procedures for getting specialty care and care coordination or case management.

• Parents want and need clear information from health plans about health plan benefits and how to get the covered services for their child, where to go with complaints and appeals, and about other available resources that will help them meet their child’s needs.

About Providers and Quality of Care

• The majority of families of children with special health care needs in this study feel positively about the quality of their doctors.

• Many children who need other specialty providers do not have adequate access to them, particularly to quality mental health providers, therapists and home health providers.
Families face a confusing maze of services from health plans, school systems, state agencies and private agencies that are not well coordinated.

It is often left to families to figure out who will provide and pay for services such as physical, occupational, speech, and mental health therapies. Payment responsibility needs to be clarified among the multiple possible payers so that children are not left un-served while agencies and programs try to decide who will pay for what.

Coordination of care and communication among providers are essential and must be improved to ensure quality care for children with special needs. These services need to be improved within individual health plans, agencies and programs, as well as across all systems that serve children with special health care needs.

Many families provide large amounts of complicated health care for their children at home, and need more support than they now receive. The impacts of a child with special health care needs on a parent’s job, finances and time must be recognized and public policies must address these impacts.

Children with health conditions that are unstable and severe, and particularly children with autism, have needs that are not well met by the present approaches of health plans, government programs, and community agencies.

Families of children with special health care needs require more information and help in order to ensure a health system that works well for their child and family. Parents consistently spoke in the survey about how other families were often their most important source of information. An established means for parents to learn from other parents needs to be assured.
What other information is available?

The voices of the families who participated in this study have provided invaluable information to the research and study of families’ experiences with health care. This information will help to form the core of our understanding of the present and planning for the future for children with special needs.

Our sincere thanks to all the families who filled out the survey, as well as the Family Voices State Coordinators and the staff of the Title V Children with Special Health Care Needs Programs in the participating states. The information could not have been collected without their help.

More information about this study can be found on the Family Voices website: www.familyvoices.org. The Family Voices national office can put you in touch with a Family Voices Coordinator in each state that you may contact for further information.

Other information about this project and project reports can be obtained by contacting:

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The report was designed by Kathrine Cruz, Family Voices at the Federation for Children with Special Needs, Boston, MA. The graphic images within this report are from www.disabilityart.com.