



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

Your Voice Counts!!
Family Survey Report to
California Participants

May 2000

FAMILY VOICES

At the Federation for Children with Special Needs
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Background

on the Family Survey in California

In late 1998, Family Voices and Abt Associates Inc. conducted a survey of parents of children with special health care needs in California, extending a national survey conducted in 20 states by Family Voices and Brandeis University. The purpose of the survey was to assess the health care experiences of children with special health care needs and their parents, and to see whether experiences were different for certain children, such as those in managed care plans or those with parents who speak Spanish. 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, along with many of their insightful comments.

- The survey, *Your Voice Counts!!*, was sent out to 7,100 families randomly chosen from California Children's Services (CCS) mailing lists and the membership lists of six California family resource organizations. 954 parents eligible to participate in the survey completed and returned the questionnaire, 153 of which were in Spanish.
- Responses came from Los Angeles, San Diego, Sacramento and Fresno counties and two rural areas in the state¹. These areas were selected in order to include geographic diversity.

"...Everyone deserves the best health care. It's discriminatory that some can't see the doctors they want because they can't afford it..."

"Parent of a child with cerebral palsy enrolled in a private managed care plan."



¹The data in this report are weighted to adjust for the different sizes of CCS mailing lists and membership lists of family organizations in each county.



Who

are the children and families?

Children with special health care needs in California whose families answered this survey had a variety of conditions. Most of the children had multiple conditions of a moderate to severe level².

- Two-thirds of the children were boys. Three-fourths of the children were between the ages of 1-14. Nearly half were Hispanic, a proportion that roughly mirrors the entire state, as did the 10% of the children who were African American. One-fourth were white and 8% were Asian, a slightly smaller proportion than the state average for those two groups. Five percent identified themselves as multiracial and 1% were Native American.
- Most children were affected by more than one condition: 37% had two or three conditions, 53% had four or more conditions. The most common conditions were developmental delay, cerebral palsy, orthopedic problems, allergies, vision impairment, mental retardation and behavioral problems. Fourteen percent of the children were technology dependent or assisted, needing such things as a feeding tube, shunt, or ventilator, etc.
- Over three-fourths of the children were described by their parents as having a moderate to severe level of disability and two thirds had special health care needs that were not stable.

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

- Eighty percent of those filling out the survey were mothers. A quarter of all respondents worked full time and 15% worked part-time. Over half the children (57%) lived in households with incomes below \$20,000, while 17% lived in households with an annual income of \$50,000 or more.
- Almost three quarters (73%) of the families lived in city/urban communities, 15% in suburban areas and 8% in rural areas. Nearly one-fifth (19%) of the families had another child with special health care needs.

²The findings from this survey should be interpreted with caution for several reasons. First, because of the low response rate, the responses may not be representative of all children from the CCS and family organizations in the sample. Second, children from participating organizations may not represent all children with special health care needs in California.





What

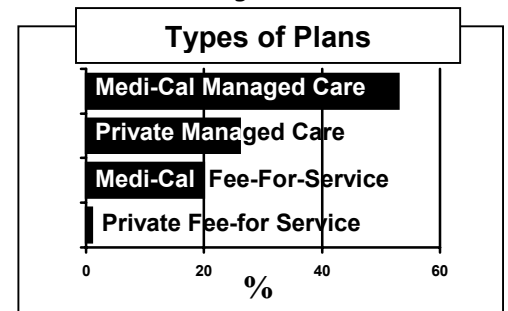
kind of health care coverage do these children have?

Many children in the study had health insurance paid for by employers, families, and/or government programs, such as Medi-Cal and California Children's Services (CCS).

- Among the children in this study only 3% had no health insurance at the time of the survey, but 10% had been without insurance at some point in the past 12 months.
- About two-thirds of the children were enrolled in Medi-Cal. Over one-fifth had health insurance paid for by a parent's employer and 6% had insurance paid for fully by their family.
- About two-thirds of the children had both primary coverage and a secondary source of health coverage, primarily CCS.

Most children were enrolled in health coverage with managed care features.

- Although nearly half (46%) of the families didn't know whether their child was in a managed care plan, most of the children (72%) were in a plan with at least one feature of managed care, such as having a network of doctors or requiring a primary care doctor.
- More than half (53%) of children in the survey were enrolled in Medi-Cal managed care, 26% were in private managed care, 20% were in Medi-Cal fee-for-service and only 1% were in private fee-for-service.



The children in this survey received a range of services from a complicated patchwork of health plans, government programs, and agencies and/or school systems.

- About two-thirds (68%) of the children in the survey received services from CCS. CCS was the most common payer for all types of therapy, except for speech therapy which was paid for mainly by schools and early intervention programs.
- Only 47% of the children up to the age of three received early intervention services. Over half (56%) of the children over age five received specialized services in school, 42% received services from the California Department of Developmental Services Regional Centers, and 3% received services from the California Department of Mental Health (DMH).
- Over a third (38%) of the children received Supplemental Security Income (SSI).



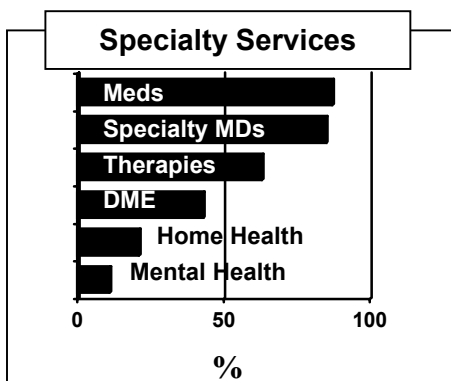
HOW

often do these children use health care services? What kind of care do they use?

The children in the survey used primary care providers, specialists, and hospitals often in the preceding year, almost twice as often as children without special needs.

- Almost all children had seen a primary care provider at least once. Almost half had seen a primary care provider six or more times in the preceding year.
- Almost all children had seen a specialist at least once. One-fourth had seen a specialist six or more times in the preceding year.
- Half of the children had been hospitalized at least once, but one-tenth had been hospitalized three or more times in the preceding year.
- Half of the children had been treated in the emergency room, while 15% had emergency room treatment three or more times in the preceding year.

Almost all of the children surveyed needed specialty healthcare services in the preceding 12 months.



- Eighty seven percent of the children needed prescription medications (Meds); 85% of the children needed specialty doctors; 63% needed therapy services (occupational therapy, physical therapy, speech therapy, etc.); 43% needed durable medical equipment (DME) (wheelchairs, ventilators, hearing aids, etc.); 21% needed home health services, and 11% needed mental health services.
- Parents said: 66% of the children needed dental care; 41% of the children needed disposable medical supplies (catheters, diapers, etc.); nearly a third (30%) needed nutritional counseling; and 27% of the families needed respite care.

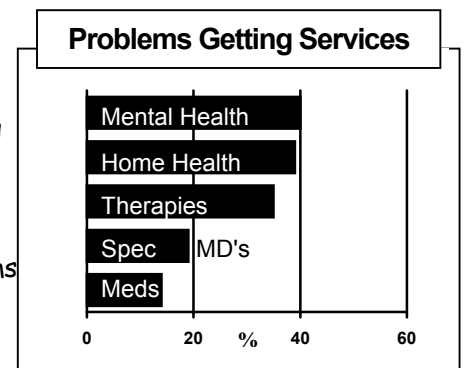


What

kinds of problems are families having getting specialty services?

A large number of parents reported having trouble getting specialty services for their child, particularly mental health services, home health services, and therapy services.

- Children with mental health needs had the most problems (40%) getting the care they needed. Within that group, children with behavior problems and/or Attention Deficit Hyper Activity Disorder (ADHD) had more problems receiving mental health services.
- Two-thirds of the children who received mental health services from the Department of Mental Health reported having problems getting services, compared to 8% of children who received mental health services elsewhere.
- Of those children needing home health care, 39% reported problems. Of those with problems, half had insurance that wouldn't pay for home health care. Fifty one percent of the families reporting problems had trouble getting payment for enough home health care hours.
- Of children needing therapies, 35% reported problems. The most common problem for children who needed some kind of therapy was that they did not get the therapy they needed. Lack of coverage for occupational therapy and speech therapy was the second most common problem followed by difficulty getting a referral and an adequate number of visits to meet their child's needs.
- Children whose special health care needs were not stable were about twice as likely to have problems getting services, (specifically accessing specialty doctors, medications, and therapy services) as children whose conditions were more stable.
- Of children needing care from specialty doctors, 19% reported problems getting these services. Of children needing prescription medications, 14% reported problems.



"...Physical therapy is not, nor will be, covered by Medi-Cal, nor probably by a private plan. I Pay \$500-600 per month (myself) for the service for my son-since it would not cause my son `to recover'. The fact that it helps him not to become more impaired is discounted."

Parent of a child with cerebral palsy enrolled in a Medi-Cal managed care plan

How

well are children's services coordinated?

Many parents said they were not aware of any formal coordination of benefits between their child's primary health insurance and their secondary insurance. Several parents expressed frustration with the fragmented system, and the time and skills it takes them to understand and organize everything.

"... There is no coordination. They send the bill to each other, back and forth, until I get really angry."

Parent of a child enrolled in a Medi-Cal managed care plan and CCS

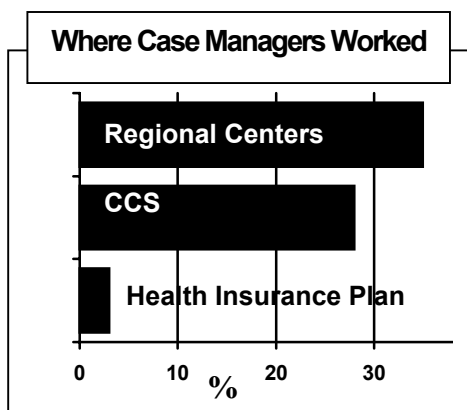
"... They don't coordinate the benefits. I have to call and send information every time."

Parent of a child with behavior problems enrolled in a private managed care plan and CCS

"... The coordination of benefits is a complex mess. Each agency has its own case managers and budgets, so there is much duplication of effort. Furthermore, each agency has no idea what the other agency is doing. Each agency wants to be the payer of last resort, so having something like a wheelchair approved is a very major hassle for families."

Parent of a child with cerebral palsy enrolled in a private managed care plan

Most parents had to coordinate the many systems and payers of health care for their children by themselves, sometimes with great difficulty. Even when parents had case managers, many reported not getting the information and assistance they needed.



- Only about half of the children had a case manager, most of whom were employed by the regional centers (35%) or CCS (28%). Only 3% of the case managers were employed by a health insurance plan

"...I mostly do all coordinating between doctors and CCS and Medi-Cal....I experienced the 'run around' with many places who supposedly should be helping me..."

Parent of a child with developmental delay enrolled in a Medi-Cal managed care plan



The services that parents received from case managers varied greatly depending on who the case manager worked for.

- Case managers from private plans were better at helping parents understand the benefits of that plan. Case managers who worked for public agencies provided more assistance with coordinating care, identifying other community based programs and resources, and getting SSI.

"...For approximately two months, I have [had] a new coordinator for my daughter. She doesn't call or visit with any information. I had to call her so she could connect me with the program that I wanted."

Parent of a child with cerebral palsy enrolled in a Medi-Cal managed care plan

When care coordination worked, parents found it very helpful.

"...My caseworker is wonderful. She and I chat on the phone whenever I have concerns. She goes to Individual Education Plan (IEP) meetings with me and helps me deal with Medi-Cal, etc."

Parent of a child with developmental delay enrolled in a private managed care plan

Many parents reported that they found information themselves or through other parents to better coordinate their child's care and identify resources.

"...I have done a lot of independent research regarding all my children's needs. I have learned how to coordinate the teams who provide services to this child and my ADHD child. I have had to rely on my own so much I have become able to help others. Some of the school officials that I have worked with have sent others to me for help. (I have a high school education and am a stay at home mom. I've learned a lot on my own to learn the system.)"

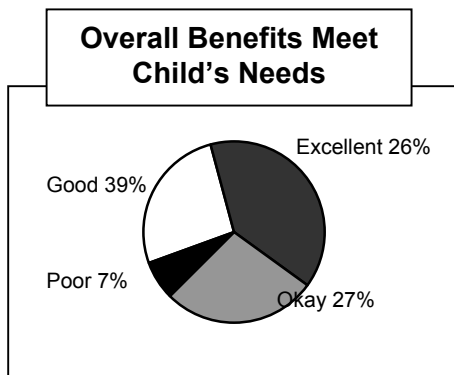
Parent of a child with asthma enrolled in Medi-cal fee-for-service



HOW

satisfied are parents with their child's primary health insurance plan?

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



- Forty four percent of the families said they were "very satisfied" with their child's primary plan; 42% were "somewhat satisfied", 12% were "somewhat dissatisfied," and 2% were "very dissatisfied."
- When asked if the plan's benefits met their child's health need, only 65% gave the plan a good or excellent rating.
- Families reported that their child's primary plan did a better job of providing access to quality hospitals and doctors than to specialists such as therapists.
- Over half of the parents were dissatisfied with the lack of clear information explaining services covered by the plan. One-fourth gave their plans a poor rating concerning information needed to file a complaint.
- Most parents were dissatisfied with the lack of "family-centeredness" of their primary health plan. Parents were most dissatisfied with the lack of information or newsletters about issues of interest or resources outside of their plan. Many were dissatisfied with or did not know whether their plan offered parent support groups or gave parents an opportunity to give advice to the plan.
- Parents whose child had a primary care doctor were most satisfied, whether it was required by the plan or not.

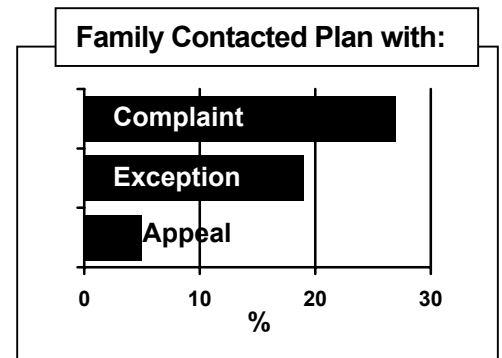
"...I like Medi-Cal because I can see doctors from different HMOs without a problem, all medication my daughter takes is O.K. I don't like that I work to find doctors for (daughter's) needs. And that they did not cover daughter on therapies."

Parent of a child with developmental delay enrolled in a Medi-Cal managed care

plan

Over a quarter of families had contacted their plan in the past year with a problem.

- Twenty seven percent of the families had called or written their plan with a complaint or problem, of these 26% of the problems had not yet been resolved, one-third were resolved, but not to the family's satisfaction. When parents who reported problems with their child's plan were asked to give more information, about one-third of the comments concerned denials of care, payment or reimbursement.
- Nineteen percent had asked for an "exception to policy." Of these, one-third were not yet resolved and one-third were not resolved to the family's satisfaction.
- Five percent of the families had filed a formal grievance or appeal. Of these, the majority had been resolved to the family's satisfaction.



The more managed the plan, the less satisfaction reported by families.

- Restrictions on coverage and limitation on provider choice appeared to be the leading reasons for dissatisfaction with the child's health plan.

"...We wanted coverage with the neurologist she had had for 10 years. But all of a sudden (this neurologist) wasn't on the plan. Our other choice was the neurologist who misdiagnosed her disorder and put her on medication which made her worse."

Parent of a child with sensory integration disorder in a private managed care plan

"...I want him to see the best - I want to go with the recommendations by those I trust. My son's cerebral palsy is relatively mild at this point and the better the care now, the better his chances are for near or complete resolution. [He] can't see the orthopedist I'd like without changing groups. Second opinion neurologist required letter from pediatrician as well as an authorization letter plus EEG, which requires yet another authorization letter, etc."

Parent of a child with cerebral palsy enrolled in a private managed care plan

In general, parents whose children were covered by Medi-Cal managed care plans were more satisfied than parents whose children were in private managed care plans.

- Parents of children in Medi-Cal managed care plans were more satisfied than parents of children in private managed care plans in a number of areas: benefits that met their child's needs; access to quality hospitals; skilled and experienced primary care doctors and specialists; emergency care and informational materials.

Parents of children in Medi-Cal fee-for-service plans were more satisfied in several areas than parents of children in Medi-Cal managed care plans.

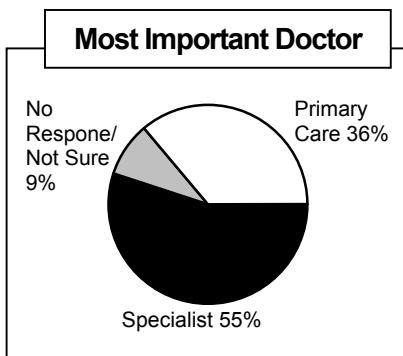
- Parents of children in Medi-Cal managed care were less likely to be satisfied than parents of children in Medi-Cal fee-for-service in two areas: access to skilled/experienced doctors and specialists and making it easy to complete paperwork.



HOW

satisfied are parents with their child's primary care provider and the doctor most important to their child's care?

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



- Eighty percent of families said that their child had a primary care provider and 93% said that this primary care provider had the skill and experience that is needed to care for their child. Eighty seven percent of families rated their child's most important doctor as "good" or "excellent" on providing quality care.
 - Over half of the parents said that a specialist was the doctor most important to their child's care.
 - About a third of the families gave lower ratings when asked about the doctor being available for advice over the phone, being easy to reach in an emergency.
- The majority of parents gave good or excellent ratings to this doctor for his/her ability to show respect for their child, spending enough time with the child, explaining the child's health needs, and including the family in decision making.
 - A large portion of parents indicated that "they did not know" about the amount of communication the doctor had with other systems that provide care for their child such as schools or early intervention programs.

Some parents were more satisfied than others

- Parents who chose their child's doctor were more likely to be satisfied with that doctor's support, communication, and partnership with the family in decision making than families who did not choose their child's doctor.
- Parents of children with moderate or severe disabilities and unstable special health care needs were less satisfied with care from their most important doctor.
- Parents who responded in Spanish were less satisfied than those who responded in English in the following ways: the overall quality of care from their child's doctor, the doctor's communication with the family, and waiting times. However, parents who responded in Spanish were more satisfied with their doctor's respect for their child and the family than parents who responded in English.
- Parents of children in Medi-Cal managed care plans were more satisfied with their child's doctor's overall quality of care than parents of children in private managed care plans.

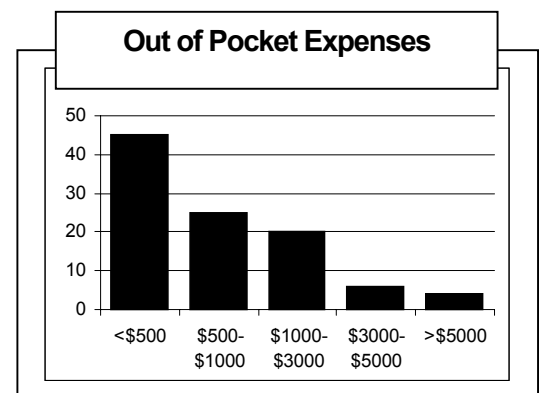


What

kind of impact does a child with special health care needs have on a family?

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

- Over half of the parents reported spending some time each week providing health care at home. One-fifth spent 20 or more hours per week providing this care.
- Almost all of the parents spent time each week arranging and coordinating their child's care, with 41% spending five or more hours per week in care coordination activities.
- One-third of the parents reported that their child's health conditions caused financial problems; 28% said they stopped working; and 37% cut down the hours they work.
- Almost half of the parents reported spending between \$500 and \$3,000 out of their own pocket for the special health care needs of their child in the past year. One-tenth said they spent \$3,000 or more.
- Most of the children in this survey had missed more than five days of school in the last 12 months; 25% had missed six to fourteen days; and 15% had missed more than thirty days of school because of their special health care needs.



"Don't give us such a run-around! Find out what our lives are like and be helpful - do not add more stress by making us jump through hoops just to see an appropriate medical professional." Parent of a child with head injury enrolled in a private managed care plan

"Allow the family to retain assets that can allow them to be self-supporting while their child's medical needs are met. There is no reason for a family to fall below the poverty line because a child needs special attention."

Parent of a child with one kidney enrolled in Medi-Cal fee-for-service

What

advice do families in the survey have for other parents of children with special health care needs?

Parents advised careful examination of health coverage, including asking a lot of questions about the plan.

"...Make sure you know you are made aware of exactly what you're financially responsible for in all situations, from office visits to emergencies."

Parent of a child with allergies/sinus trouble enrolled in Medi-Cal fee-for-service

"...Check all the fine print and if you have any problems regarding benefits - ASK! And if the answers aren't to your understanding, ask again. Don't be afraid to contact insurance companies directly and speak to someone with the knowledge needed to help. Also, speak to the parents of these children if you have any questions before getting a denial for a referral or continued care. We know our children best."

Parent of a child with digestive/gastrointestinal disorder enrolled in a private managed care plan

More than one-fifth of parents who responded in English advised families to make sure the plan they chose allowed for flexibility of choice, especially for choosing doctors and specialists.

"...Make sure that you choose a plan, if possible, that has the most flexibility in choosing doctors, specialists and hospitals."

Parent of a child enrolled in a private managed care plan

"...Make sure they will let you continue with doctors already familiar with your child. Make sure they let you see doctors knowledgeable with your child's medical condition."

Parent of a child with autism enrolled in a private managed care plan

Some parents who responded in Spanish advised parents to make wise provider choices based on their ability to provide bilingual services.

"... To choose a good medical group, nice, kind and with bilingual staff."

Parent of a child with allergies enrolled in Medi-Cal fee-for-service.

"..Only choose places where they can speak in their own language about the programs and where they can receive instructions and advice for their patients."

Parent of a child with scoliosis enrolled in Medi-Cal fee-for-service.



What

kind of advice do parents have for their child's health plan?

Parents wanted expanded coverage, a choice of doctors and the designation of a specific person who knows how the plan operates that families can contact when they need help.

"...Listen to the parents, we know our kids better than anyone else. Don't be afraid or intimidated by special needs children because they just need a little tender loving care."

Parent of a child with epilepsy/seizure disorder enrolled in a private managed care plan

"...To be able to see the same (one or two) doctors - always! When I need a same day appointment and can't see my primary care doctors it is frustrating to have to explain his whole medical history over and over again."

Parent of a child with seizures and microcephaly enrolled in a private managed care plan

"...Provide a case manager or specific representative that I can contact instead of dealing with a different person each time I call."

Parent of a child with arthrogryposis bulbar palsy enrolled in a private managed care plan

"...Have RNs who are familiar with the disabilities answer a special needs phone line at Medi-Cal. Have someone with the knowledge of what is covered, by which agency and tell you straight out what is needed i.e. referrals, to make sure your child's needs get met."

Parent of a child with Down Syndrome enrolled in a Medi-Cal managed care plan

One-tenth of parents who responded in Spanish requested that the plan hire more bilingual staff and/or providers.

"... To offer sufficient bilingual skilled personnel to communicate and understand well what the users need."

Parent of a child with cerebral palsy enrolled in Medi-Cal fee-for-service

"... To have skilled personnel, and not partially bilingual; a telephone number with a 24 hour service to contact them, because sometimes we can't get in touch with them (during working hours)."

Parent of a child with mental retardation enrolled in Medi-Cal fee-for-service



In conclusion, what does the family survey tell us?

While some pieces of the health care financing and delivery system are serving these children well, other pieces 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, the experiences of these children with special health care needs and their families are reflections of how well health systems in California are performing and should be monitored carefully.
- The comprehensive benefit package of Medi-Cal provides essential services for children with special health care needs and should serve as a model benefit package for all children needing specialized health care services whether publicly or privately funded.
- Medi-Cal administrators should investigate why parents of children with Medi-Cal managed care plans were less satisfied than parents in Medi-Cal fee-for-service plans with the provision of skilled and experienced primary and specialty care.
- For some children whose primary health coverage benefits are limited, secondary health care coverage, like CCS, is essential.

About Health Plans

- Children with special health care needs require flexibility in health care plans such as choice of doctors and specialists, streamlined procedures for accessing specialty care, and care coordination/case management.
- Parents want and need clear information from their health plans about health plan benefits, how to get covered services for their children, where to go with complaints and appeals, and 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, especially if they can choose them.

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- Many children who need other specialty providers do not have adequate access to them, particularly to quality mental health providers, experienced therapists and skilled home health providers.
 - The needs of parents who responded in Spanish need to be further investigated, particularly around issues of communication with providers and quality of care.

About Coordination of Care

- Families in California face a confusing and fragmented maze of services from health plans, school systems, state agencies and others programs such as regional centers, CCS and DMH. This adds to the complexity of their lives, and their frustration with systems of care meant to serve their children.
- It is presently often left to families to figure out who will provide and pay for therapies such as physical, occupational, speech, and mental health. Payment responsibility among the multiple possible payers must be clarified so that children are not left unserved while agencies and programs negotiate among themselves about payments.
- Case management services, coordination of care and communication among providers are essential for this group of children and must be improved to ensure quality care. Improvements within individual plans, agencies and programs, and across systems that serve children with special health care needs are necessary.

About Children & Families and Information for Families

- Many families provide significant amounts of complicated healthcare for their children at home. They 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 unstable and/or severe health and behavioral needs, are not receiving adequate services from health plans, public programs, and community agencies.
- Families of children with special health care needs require more information and help in their own language in order to ensure a health system that works for their children and families. Parents consistently spoke in the survey about how other families were often their most important source of information, and 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 that will help our understanding of the present and planning for the future for children with special needs. More information about this study can be found on the Family Voices website: www.familyvoices.org.

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

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More information about this study can be found on the Family Voices website:
www.familyvoices.org.

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