

Executive Summary

Managed care is becoming the most common form of health insurance among most population groups, including children with special health care needs. Some experts have been concerned that the quality of care for those insured by managed care plans will be lower compared to those with traditional fee-for-service insurance, particularly in terms of access to specialists and medical care, coordination of care, and parental satisfaction.

In late 1998, Family Voices and Abt Associates Inc. conducted the largest survey to date of parents of children with special health care needs in California. The main research questions were related to describing these families' experiences with the health care system, including access to care, utilization, coordination of care, and parental satisfaction, as well as describing the impact on families of having a child with special health care needs. A sample of 7,100 children in four counties and two rural areas was drawn from the membership lists of family organizations and from the client databases of California's Title V Children with Special Health Care Needs program, California Children's Services (CCS). Sixteen percent (954) of eligible parents completed and returned the mail survey. This report contains both descriptive results and comparisons of children's experiences in managed care vs. those not in managed care and comparisons of Spanish-speaking vs. English-speaking parents.

Major Findings

Characteristics of children in the study: Most of the children whose parents participated in this study were affected by multiple conditions, were moderately to severely disabled, and had unstable special health care needs.

- The most common condition was cerebral palsy and other neuromuscular conditions, affecting almost one-fifth of children.
- The majority of children were affected by more than one condition: over one-third had two or three conditions, and over half had four or more conditions.
- Fourteen percent of children were technology-dependent.

Health insurance coverage: Most children were enrolled in Medi-Cal and CCS, and most were in managed care plans.

- Almost all children had a primary health insurance plan, with only three percent uninsured at the time of the survey, but one-tenth were without health insurance at some point in the last 12 months.
- About two-thirds of the children were enrolled in Medi-Cal and two-thirds were enrolled in CCS.
- Over four-fifths (82%) of children were enrolled in a managed care plan.

Utilization of providers and hospitals: Utilization of providers and hospitals in the last 12 months was high.

- Almost all children had seen a primary care provider (PCP) and a specialist at least once. Forty-three percent had seen a PCP six or more times, and 28 percent had seen a specialist six or more times.
- Half of children had been hospitalized at least once for a medical problem and one-tenth had been hospitalized three or more times.
- Half of children had been treated in the emergency room, 15 percent had been treated three or more times.
- Utilization was significantly higher among children with more severe levels of disability and more unstable special health care needs.

Need for specialty services and problems accessing services: In the last 12 months, many children had a high level of need for specialty services, and a significant proportion of parents reported having trouble getting some services for their child.

- Over fourth-fifths of children needed specialty physicians or prescription medications, two-thirds needed therapy services (occupational therapy, physical therapy, speech therapy, etc.), almost half needed durable medical equipment, one-fifth needed home health services, and one-tenth needed mental health services.
- A large proportion of parents reported having difficulty getting mental health services (40 percent), home health services (39 percent), and therapy services (35 percent) for their children.
- Children whose special health care needs change all the time were about twice as likely as children with stable special health care needs to have problems getting prescription medications, and services from specialty physicians and therapists.
- Children with behavior problems and/or ADD/ADHD, and children receiving services from the Department of Mental Health were more likely to have problems accessing mental health services.

Coordination of benefits and care: Most parents received little help to coordinate the multiple systems and payors of care for their children.

- Many parents reported that they were not aware of any formal coordination of benefits between their child's primary and secondary insurance such as CCS.
- Only half of children had a case manager, most of whom were employed by a state agency such as the regional centers (35 percent) or CCS (28 percent). Only three percent of case managers were employed by a health insurance 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.

- Less than two-thirds of parents thought the case managers had a good understanding of their child's needs.
- Many parents reported that they must find information themselves through other parents in order to better coordinate their child's services and identify resources.

Satisfaction with primary health insurance: About two-thirds of parents were satisfied with their child's health plan in terms of capacity (such as access to quality hospitals, primary care providers, and specialty physicians) and their overall benefits package, but less than one-third to one-half were satisfied in terms of providing clear informational materials about the plan and even fewer were satisfied with the family-centeredness of the plan.

- **Differences by level of disability and stability:** Parents were more likely to be dissatisfied with their child's plan if their child was more severely disabled and had less stable special health care needs.
- **Differences by type of payor/plan:** Satisfaction was lower among parents whose children were in private managed care plans compared to Medi-Cal managed care plans in terms of benefits, capacity, approving emergency care, and providing informational materials. Among those in Medi-Cal, satisfaction was lower among parents whose children were in managed care plans compared to those in fee-for-service plans in terms of the plan providing skilled/experienced PCPs and specialist physicians, and making it easy to complete paperwork.
- **Differences by feature of plan:** Satisfaction was lower among parents whose child's plan had managed care features such as having a network of providers or requiring approvals for specialty care. However, satisfaction was higher among parents whose child had a primary care provider, regardless of whether it was required by the plan.
- **Differences by language of parent:** Among Medi-Cal children, Spanish-speaking parents were more satisfied with their child's plan compared to English-speaking parents.

Satisfaction with physician most important to child's care: Most parents were highly satisfied with their child's physician, but fewer were satisfied in terms of availability and coordinating with other providers.

- Parent satisfaction with their child's physician was highest for communicating with their child and with parents and showing respect for their child and their culture. Satisfaction was lower for availability, coordinating with other service providers, and for providing updated materials on research that may help their child.
- **Differences by level of disability and stability:** Satisfaction was lower among parents of children with moderate or severe levels of disability and unstable special health care needs.
- **Differences by type of payor/plan:** Among Medi-Cal children, parents of those in managed care were less satisfied with their physician communicating with other providers and agencies compared to those in fee-for-service. Compared to Medi-Cal managed care, parents of

children in private managed care were less satisfied in terms of the overall quality of care, availability, and providing updates on medical research.

- **Differences by language of parent:** Spanish-speaking parents were actually more satisfied with their physician respecting their child and their culture compared to English-speaking parents, although they were less satisfied in terms of the physician communicating with them and giving them reassurance/support, waiting times, and the overall quality of care.

Family impact: Having a child with special health care needs has had a significant impact on families, affecting their finances, jobs, and time spent providing care at home.

- One-third of parents agreed that their child's conditions are causing financial problems, 28 percent said they stopped working, and 37 percent cut down the hours they work.
- Over half of parents reported spending some time every week providing health care at home.
- Almost all parents spent some time every week arranging and coordinating their child's care, with 41 percent spending five or more hours per week.
- Over half of children missed a week or more of school in the past year because of their special health care needs.

Conclusions and Implications

Children with special health care needs are a small but significant part of our nation's population of children. The results of this family survey suggest that while some parts of the health care financing and delivery system are serving these 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 and private agencies. The experiences of these children with special health care needs and their families are reflections of how well the health system in California is performing related to public policy, health plans, providers, coordination of care, and families.

Public Policy

- The comprehensive benefits 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 in Medi-Cal managed care plans were less satisfied than parents in Medi-Cal fee-for-service 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.

Health Plans

- Children with special health care needs require flexibility in health care plans such as a choice of physicians and specialists, streamlined procedures for accessing specialty care, and care coordination or 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 about other available resources that will help them meet their child's needs.

Providers

- The majority of families of children with special health care needs in this study feel positively about the quality of the physician most important to their child's care.
- 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.
- The needs of parents who responded in Spanish need to be further investigated, particularly around issues of communication with providers and quality of care.

Coordination of Care

- Families in California face a confusing and fragmented maze of services from health plans, school systems, state agencies and other programs such as regional centers, CCS and the Department of Mental Health.
- It is often left to families to figure out who will provide and pay for therapies such as physical, occupational, speech, and mental health. Payment responsibility needs to be clarified among the multiple possible payers so that children are not left unserved while agencies and programs decide among themselves who will pay for what.
- Case management services, 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 both within individual plans, agencies and programs, as well as across systems that serve children with special health care needs.

Children and Families and Information for Families

- Many families provide large amounts of complicated health care for their children at home, and need more in-home 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, as well as children with ADHD and/or behavior problems, have needs that are not well met by the present approaches of health plans, public programs, and community agencies.

- All families of children with special health care needs require more information and help in order to ensure a health system that works for their children and families. Families need more information about their health plans and how they work, about public programs and how to access them, and about community resources that will help them care for their vulnerable children. Parents consistently spoke 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.

