



The Health Care Experiences of Families of Children with Special Health Care Needs: Summary Report of Findings from a National Survey

Background on the Family Survey

- In 1998, Family Voices and Brandeis University conducted a national survey of 2,220 families of children with special health care needs in 20 states. The survey was sent out to randomly selected families in state Maternal and Child Health Programs for Children with Special Health Care Needs, and families on the mailing lists of Family Voices.

Who are the children and families?

- The children in the survey had a wide variety of conditions, including developmental delay, cerebral palsy, behavioral problems, seizure disorders and asthma. Most children were affected by more than one condition. Seventeen percent were technology dependent. One third of the children (35%) were described by their parents as having a severe health condition.
- More than half of the children were boys. The children were between the ages of 3 months and 18 years. Over a quarter were from minority backgrounds, including 11% African American, 9 % Hispanic, 6 % multi-racial, 2 % Asian or Pacific Islander and 1.5% Native American.
- The average income for families was \$34,327. About a third of the families lived in households with incomes below \$20,000. A little more than a third lived in urban, almost a third in suburban and not quite a third in rural communities.

What kind of health coverage do these children have?

- Children in the study had health insurance coverage paid for by employers, families and/or government programs. A third of the children had a secondary source of health coverage, most often a public program such as Medicaid.
- The children were covered by different types of plans including both managed care and fee-for-service. Over half said that their plan had managed care features such as requiring a primary care provider, or requiring referrals for specialized health services.
- They also received health services from a number of other government programs such as schools, early intervention programs, state Maternal and Child Health Programs for Children with Special Health Care Needs, Departments of Mental Retardation/Developmental Disabilities (MR/DD), and Departments of Mental Health. Over a third received SSI
- Many specialized services, particularly therapies, mental health and home health were paid for by a combination of payers including health plans, schools, other public programs and families themselves.

How often do these children use services, and what kind of care do they use?

- The children in the survey used health care services extensively: in the preceding year about 20% had seen their primary care doctor 8 or more times and about 20% had seen an outpatient specialist 8 or more times; 44% had been hospitalized, and 11% had been hospitalized 3 or more times; 39% had used an emergency room, and 14% had used an emergency room 3 or more times.
- In the preceding 12 months, over three quarters of these children had used specialty doctors and prescription medications, almost half received therapies, over a quarter received home health services, and almost a fifth received mental health services. Families reported that almost half needed durable medical equipment, over a third needed disposable medical supplies, a quarter needed nutritional counseling, and almost a third needed respite services.

What kinds of problems are families having getting specialty services?

- Almost half of children receiving home health care and those receiving mental health services had encountered problems such as finding skilled and experienced providers and getting adequate coverage.
- Slightly over a quarter of children receiving therapies had problems such as caps on visits and lack of skilled and experienced providers. Around a fifth of children seen by specialty doctors had problems such as getting appointments, finding providers, and/or being denied coverage.

- Families also reported problems and/or unmet need with respite services (46%), nutritional supplements (38%), durable medical equipment (31%), and disposable medical supplies (26%).

How well are these children's services coordinated among health plans, government agencies, and schools?

- For the families who had a case manager (49%), some case management services were helpful. Many families, however, reported not getting the care coordination that they needed.
- Many parents reported that they coordinated the numerous systems and payers of health care for their children themselves, sometimes with great difficulty. To better coordinate their child's care and to identify resources, many parents found information through other parents.
- When case management worked, families found it very helpful. However, families expressed frustration with care coordination that did not work.

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 health plan, although they expressed less satisfaction when asked specific questions about the plan.
- On providing benefits that meet their child's needs 22% rated their plan as excellent and 38% rated their plan as good; on providing skilled and experienced specialists such as PT, OT and speech 25% said excellent and 28% said good.
- Less than half of families gave good ratings to their plan for provision of information about what benefits were covered, how the plan worked, or information about services outside the plan that might help the child.
- Families were less satisfied when their plan was more "managed," such as requiring approvals for specialty care or limiting the choice of doctors that parents could use.
- Parents whose child's primary plan was Medicaid were more satisfied and had fewer problems than parents whose child was in a private health care plan.
- Families of children with mental health, behavioral problems and autism were the most dissatisfied with their plans.
- Over a third of families had contacted their plan in the past year with a problem.

How satisfied are parents with their 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.
- Almost half of the parents said that a specialist rather than a primary care doctor was their child's most important doctor.
- A third of the parents gave lower ratings to the doctor's communication with other service systems such as schools.

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 had 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 because of their child's health conditions.
- Half of the families reported experiencing financial problems associated with meeting their child's needs. The majority of families incurred out of pocket expenses.
- 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 88% of respondents who were mothers reported spending some time every week providing health care at home. A fifth spent 20 or more hours per week providing health care at home to their child.