

Kids Caught in the Middle

Children with Severe Disabilities Go Underserved

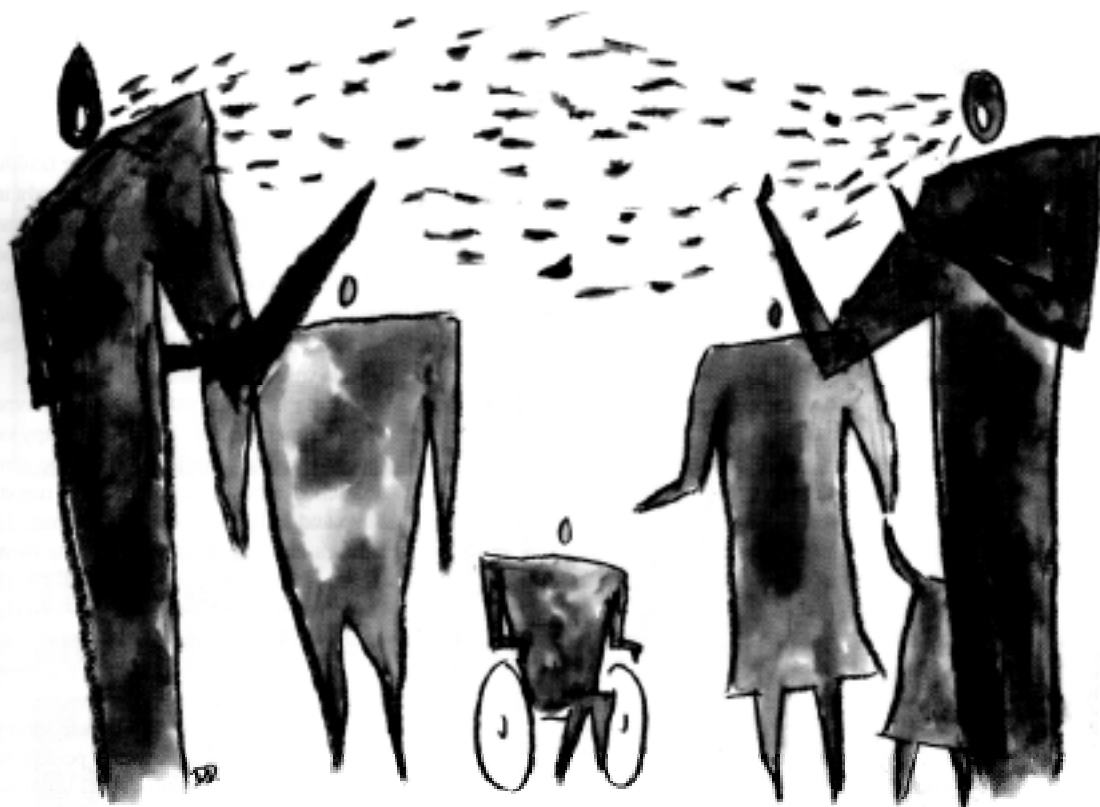


Illustration by Doug Davis

By **Mary Guthrie**

Managed care organizations cannot offer comprehensive services to the family of a child with a disability, leaving schools and family members to fund basic services such as therapy, equipment and home care.

Families of children with chronic illnesses or disabilities are satisfied with the medical care they receive through managed care, even though they suffer from tremendous stress caused by the lack of coordination among the medical, social service and educational communities, according to the results of a new study.

The study shows that schools, and not managed care organizations, are paying almost \$2,000 per child, or as much as 80 percent of therapy services received by children whose families were part of the study.

The study is the result of survey responses from 21 physicians from HealthPartners, a health maintenance organization based in Bloomington, Minnesota; 30 families who are

HealthPartners members; and four meetings of a parent advisory council convened for the study and led by Ceci Shapland, R.N., of the Pacer Center, Minneapolis.

The study was conducted by a foundation sponsored by HealthPartners, the Center for Children with Chronic Illness and Disability at the University of Minnesota, and PACER Center, working under grants from the National Institute on Disability and Rehabilitation Research and the Robert Wood Johnson Foundation to understand the challenges facing families of children with special needs.

The study identified all children who had been HealthPartners members continuously from Nov. 1, 1993, through October 31, 1994; who were between ages 1 and 21; and who were diagnosed with cystic fibrosis, cerebral palsy, muscular dystrophy, juvenile-onset diabetes mellitus, congenital heart disease, autism or Down syndrome. Then researchers calculated how much was spent on each of these 410 children over the course of a year, and where they received their services.

In addition to their HealthPartners health care, about half of

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the families received benefits through state or federal programs such as SSI, Medicaid, Vocational Rehabilitation, WIC and other programs. The survey results showed families typically paid from \$10 to \$42 per month in out-of-pocket expenses. It was also noted that about one-third of the families said the child's condition affected their ability to be employed and was a source of employment stress and reduced income potential.

One aspect of the research questioned HealthPartners member physicians about how they care for children with special needs. Most said they followed fewer than 20 children with complex medical conditions or physical disabilities. And although they enjoy taking care of these children, the physicians said they devoted 6 percent to 20 percent of their time to caring for them.

The majority of the physicians said they did not know how equipment, supplies or special services would be paid for if not by HealthPartners. "[The research] shows again that health is not connected in the system that serves these families," said Shapland. "The communication between health and other resources is not very strong."

Many of the physicians said they felt they did not have enough time to spend with complex patients to coordinate care. Despite the ambivalence of their primary care physicians, in most cases, the families felt strongly that the pediatrician played a central role in coordinating care. They also felt it was useful to have a primary care clinic for most services. But good basic medical care is only the beginning for these families.

Another aspect of the study surveyed more than 30 families on their quality-of-life issues. About 88 percent ranked stress management as their No. 1 concern, ahead of special education, equipment and mobility. The problems come from lack of coordination of services, parents said. Families spend a lot of time trying to get information about resources and benefits, as well as figuring out what they should buy, what other payers will fund, and how to access community services. Because case managers are often familiar only with the benefits offered by the institution that is paying for them, families have to advocate for other services on their own, survey results showed.

Because of the lack of communication among the health, education and social service organizations, families are caught in the middle. "If the community could come together to address what's the best way to provide services without duplication and coordinate their efforts, we might be able to offer more comprehensive services at equal or less cost," said Barbara Staub, M.D., a HealthPartners pediatrician who directed the research project.

Nearly all of the students who received occupational therapy, physical therapy or speech-language therapy received the care in a school setting, according to the report. Shapland led groups of parents from 13 families in group discussions, asking them to describe their experiences with HealthPartners and how care was coordinated with other agencies. "I felt it was very clear that education is carrying these kids," Shapland said.

In fact, the data from the parent survey indicated that schools cover 60 percent to 80 percent of the occupational therapy, physical therapy and speech and language services. In this instance, that would be an annual cost of \$400,000 to \$800,000 for 410 children who are HealthPartners members. That equates to about \$2,000 per child or two to four times the amount HealthPartners paid for that type of service for these children over the same period.

The report points out that no single HMO or MCO can unilaterally offer comprehensive services to children with disabilities. Instead, in its conclusion, the report calls for discussion of how to pay for health-related services such as durable medical equipment; occupational, physical and speech therapies; and home care services. HealthPartners is working on a plan to offer parents of children with special needs a manual describing the company's benefits, but that project has not been funded, Staub said. In addition, they are hopeful that support for primary care physicians would include resources for families of children with disabilities, but that too lacks funding at this time. ■

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