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HOME FRONT

Illness Strikes, and Insurance Falls Short

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On a Friday last May, not far from the blaze of Times Square lights, Carol and Daniel Giordano, with their daughter, Dana, 12, were waiting to cross Seventh Avenue when Dana slumped to the ground in a seizure. Mr. Giordano flagged a police car, and a passing ambulance took her to New York Presbyterian Hospital.

For the next five weeks, the family was camped out there as Dana endured high blood pressure, fevers and an induced coma to stop her seizures.

For all the uncertainty during those weeks about the sudden onset of Dana's illness, Mr. and Mrs. Giordano of Mineola, N.Y., had not yet considered how much of a financial burden a chronic disease could be: doctors' fees not covered by insurance and necessary procedures that cost the Giordanos thousands of dollars out of pocket, despite a solid insurance plan through Mr. Giordano's job as a high school principal.

Their experience is familiar to that of other

New Yorkers of varying incomes who, because of restrictive insurance plans or a lack of understanding about the complexities of today's health care costs, find themselves shouldering some or much of their families' medical care expenses.

It took several doctors, two hospitals and dozens of tests to correctly diagnose Dana's condition: complex partial seizure, a form of epilepsy. Reaching that diagnosis required tests and analysis by a number of physicians who were brought in for unscheduled consultations and were not covered by the Giordanos' insurance. "The anesthesiologist may be in the plan," but the radiologist reading the films is not, Mrs. Giordano said. "He charges me \$2,000, my insurance pays \$1,200, and I'm stuck with the rest." To help pay for costs not covered by their insurance, the Giordanos tried to buy a

To help pay for costs not covered by their insurance, the Giordanos tried to buy a secondary policy, but with no luck. Mrs. Giordano said: "Because we're already insured, forget it. They just don't do it."

Mrs. Giordano, who quit her job as a dental hygienist before her daughter became ill, said she cannot get another job to help with medical costs because Dana, now 13, needs 24-hour care for seizures that can occur seven or more times a day, and has to be driven to several therapists.

Instead, the Giordanos hope some of the services will be provided by Medicaid's Care at Home waiver program for families with children whose conditions require extensive medical care. They expect to qualify. If not, Mrs. Giordano estimates that the three brain operations that her daughter is scheduled to undergo out of network this year could easily cost the family \$30,000 in deductibles, on top of routine medical expenses. The number of Medicaid participants has increased in New York City to 2.6 million today, from 1 million three years ago, in large part because of waiver programs like those that may be open to the Giordanos, said Patricia M. Smith, first deputy commissioner for the City Human Resources Administration/Department of Social Services, which administers the city's Medicaid program.

Still, experts say many New Yorkers are not aware that waiver programs exist, despite an annual community outreach budget of \$9.5 million, or that they qualify for them. And they say Medicaid caseworkers, often unfamiliar with many of their agency's programs, can mistakenly deny coverage to families.

Medicaid is a complex program that varies between states and even counties, said Jay Nawrocki, a health care policy analyst with CCH Inc., which publishes the Medicare and Medicaid Guide. "It's hard for these folks administering the program in the intake offices on a day-to-day basis to keep up with what's going on."

Joann Colucci, a caseworker for the Giordanos and an intake coordinator at SKIP of New York (Sick Kids Need Involved People), an advocacy group for families with chronically ill members, said she had seen cases in which families " never got referred into Medicaid, and they have \$100,000 in debt or they have to mortgage their home." The Giordanos took out a \$10,000 home equity loan last year to pay for Dana's medical expenses and other unexpected costs, like hotel rooms and food for the family while she was in intensive care.

"Dana's going through such a serious illness," Mrs. Giordano said. "How do I say, 'Don't use the best doctors, but use the best ones on my insurance.'?"

This column about the local economy appears every other week. E-mail address: homefront@nytimes.com