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## Model center cares for medically fragile children

### Program hailed as better health care at lower price

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COLUMBIA--When Walter and Shawna Davis finally took their infant daughter home from Palmetto Richland Memorial Hospital on Oct. 3, 2002, they had more to worry about than diaper rash.

Jazaria Davis was 7 months old.

She and her twin sister, Jazoria, were born in March that year, three months prematurely. Each weighed less than two pounds. Doctors sent Jazoria home within weeks. But Jazaria spent the next few months sick and feeble. She was able to eat only through a tube in the hospital's neonatal intensive care unit.

Beyond the normal concerns of first-time parents, the Davises were facing years of having to deal with a complex, uncoordinated and costly health care system. "It was going to be a lot of work," Shawna Davis said. "I didn't know how we were going to do it."

Help came in a phone call the next day. Their surgeon had referred them to the Medically Fragile Children's Program.

The program focuses on some of the weakest children -- and most expensive to care for -- in the Medicaid program. In exchange for a monthly fee of \$2,250 per patient, it coordinates all of their health care from a facility in downtown Columbia.

By spending money on that coordination, the program has saved countless dollars that potentially would have been wasted in caring for Jazaria.

Both Davis children are enrolled in the program. It allows them to see a single pediatrician, ensures they receive their medications and arranges for therapy twice a week. When their parents need advice, they have one number to call at all hours of the day, and they have received extensive training on how to care for their twins.

Launched a little less than a decade ago, the Medically Fragile program is being held up as an example of what modern health care should be: better care at a lower price.

The program is winning growing national attention from hospitals and state governments yearning to figure out how it works. Its director, Pat Votava, estimates she gets at least one call a week from a state interested in learning more.

The program also is receiving some attention from Gov. Mark Sanford's office, which may hold it up as a model of how to save money by coordinating the work of multiple agencies.

Palmetto Richland started a second program in Easley with help from the Greenville Hospital System two years ago. This spring, the Medical University of South Carolina hopes to admit the first patients to its own center, which will operate out of renovated space in the old Roper North building.

The program began as a way to centralize both health care and social services for foster children. Caring for these children was costing Medicaid a bundle, mostly because of a lack of coordination among different providers and service agencies, which led to much duplication and sometimes unnecessary treatments.

The purpose of Medically Fragile is simple: Put all basic services under one roof.

The center at Palmetto Richland employs a full-time pediatrician and a local pediatric group that is on call 24 hours a day, a child psychologist, nurses, various types of therapists, a pharmacist, dietitian and educators. It also handles referrals to specialists.

Once a month, parents receive supplies for their children, including diapers, formula and prescription drugs. Parents also can get equipment such as specially designed wheelchairs or leg braces.

The savings this coordination has realized are substantial.

Before children are enrolled in the program, caring for them can cost Medicaid anywhere from \$3,782 to \$18,211 a month, more than half of which goes to hospitals for inpatient visits. After enrollment, that cost is reduced to \$2,615 to \$3,605 per month. Only 5 percent of that cost is for hospital stays.

According to proponents, if all 250 of the state's medically fragile foster children were placed in a program like this, it could save Medicaid \$6.2 million a year, and the Department of Social Services an additional \$5.5 million.

What's more, the state is getting healthier kids for its money. More than half the program's participants exceed doctors' expectations. And more special-needs foster children get adopted.

The typical adoption rate for that group is 5 percent. Among Medically Fragile patients, it's 60 percent.

Officials say the program's biggest benefit is its heavy emphasis on training parents to treat some of the more basic problems at home instead of taking their child to the costly emergency room.

Dr. Susan Luberoff, the program's pediatrician, said it's like having a health care professional with the patient at all times. She said it's a big reason the program cuts ER visits in half.

The Davises had no idea what they were going to do the day they took Jazaria home from the hospital.

Jazaria had "short-gut syndrome," because an infection shortly after her birth led to the removal of 90 percent of her gangrenous intestines. It meant that food had little time to digest. Her sister had a similar problem, but only 10 percent of her intestines were removed.

Jazaria wouldn't eat through her mouth for the first seven months of her life. Doctors considered surgery to put a permanent tube directly to her stomach, but were reluctant. "They thought she wasn't going to really make it," Shawna Davis said.

It was only after Walter Davis' mother stepped in with a mixture of applesauce and oatmeal that Jazaria ate, paving the way for her to go home.

But the syndrome meant she needed a lot of medications and doctor visits. And Jazaria had other problems, including a hip infection and an irregular heartbeat that required surgery at MUSC last year. Today, Jazaria is nearly 3. She has had surgery eight times.

Nevertheless, Jazaria looks like any other 3-year-old, a girl with a big sense of humor. She gained so much weight, in fact, that she surpassed her twin.

Once told she would eat only pureed food and no sugars, Jazaria now eats everything. "She hasn't stopped eating," her father said.

The parents believe the Medically Fragile program had a lot to do with improving their daughter's health.

"I don't think we could have made her as healthy," Shawna Davis said. "It's like a fairy tale ending for us."

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