

Posted on Thu, Jun. 11, 2009

## Dad of disabled girl has tough choice: food or diapers

BY CAROL MARBIN MILLER

[cmarbin@MiamiHerald.com](mailto:cmarbin@MiamiHerald.com)

Widowed and unemployed, Floyd Smith is struggling to house and feed his four children on \$1,000 a month in benefits.

The Miami resident's biggest expense outside of rent: diapers.

Smith, whose wife died of brain cancer last year, spends \$200 a month on diapers for his 16-year-old daughter Sharett, who has severe cerebral palsy and mental retardation. He says he can't afford the diapers and other necessities for his family, and has asked Medicaid, the state's insurance program for the needy, to help.

Medicaid administrators have refused to pay. They haven't explained why they won't pay, other than say the items aren't in the state's plan, say Smith's attorneys. In a lawsuit filed Monday, Floyd and Sharett Smith are asking a federal judge to declare Florida's Medicaid rules contrary to federal law and to order the state to pay the diaper bills for Sharett -- and, potentially, thousands of children like her.

"I don't know how we do it," Smith, a plain-spoken unemployed waiter, said of his family's efforts to make ends meet. "For a child like Sharett, I think they should take care of that for her."

"She is totally disabled," he added. "Totally."

Tiffany Vause, press secretary for the Agency for Health Care Administration, which oversees Florida Medicaid, declined to discuss Smith's suit, which names AHCA Secretary Holly Benson in her official capacity. "Unfortunately AHCA cannot comment on pending cases," Vause said.

Under federal law, states can opt out of the Medicaid program -- in which federal taxpayers foot the bill for about two-thirds of the medical bills for the states' needy -- but must abide by federal rules if they participate. Smith's lawyers say federal law is clear: Diapers must be covered for children and young adults below age 21.

### LOST IN COURT

Two other states had excluded diapers from their Medicaid plans, Arizona and Louisiana, said Monica Vignes-Pitan, one of Smith's lawyers with Legal Services of Greater Miami. Both states lost court challenges.

Diapers may not appear to be medical equipment or devices, said Miriam Harmatz, another attorney who works with Florida Legal Services. But "there is a whole other world of children who are so disabled that they are incontinent," she added. "For them, it is very much a medical issue."

Added Vignes-Pitan: "How can you send a 16-year-old girl who is incontinent to school without a diaper?"

Smith, 52, had been laid off as a waiter when his wife, Katrina Howard, was diagnosed with a brain tumor. He cared for her and their four children for the next year until she passed away on June 12, 2008 under hospice care. He said he tried to get a job, but it was important to his wife that he remain with her.

"All the time, she wanted me to be by her bedside," Smith said. "When she went into hospice, I had to be there for her to sleep. She just constantly cried. I couldn't leave her. I tried to come home and they called me and said I couldn't leave her: 'She is crying for you.'"

Howard was really the family's breadwinner, Smith said, working as a cashier at a Pollo Tropical restaurant. Since Smith has been unable to find a job in the current recession, he works 33 hours a week doing community service when the children are in school in order to receive food stamps and federal welfare benefits for the kids.

Smith also receives a little help some weeks from his church, Dayspring Missionary Baptist Church in Miami.

## **NO INSTITUTIONS**

Although under state and federal law Smith could place Sharett in an institution for the rest of her life, his lawyers say he views the alternative as out of the question. "He does not want to institutionalize his daughter," said Vignes-Pitan.

"He is totally devoted to his daughter," added Harmatz.

Sharett cannot walk, speak, use her hands or understand much of what goes on around her, her father said. She doesn't watch much TV or listen to music. She finds comfort in her three teddy bears and enjoys going in the family's car for a ride.

Her 8-year-old sister, Kayana, has become something of a mom to Sharett, Smith said, making pancakes or sandwiches and helping change the teen's diapers. "She is very, very helpful and loving toward Sharett," Smith said. "She hugs her and kisses her, and sleeps with her sometimes."

But the cost of the diapers, Vignes-Pitan said, has forced Smith to make painful choices some months: "What do you choose: food or your kid's diapers?"