US: Florida Medicaid cuts target food for disabled children

Naomi Spencer 17 March 2006

In a despicable and callous act, Florida Medicaid officials have begun denying funding for special liquid food formulas used by some children suffering from HIV/AIDS, undergoing dialysis, or living with severe physical disabilities, according to reports published in the *Miami Herald*. Thousands of children are endangered by the unannounced policy change. Doctors and dietitians have condemned the cuts.

Most at risk are children disabled with birth defects and degenerative diseases who require liquid sustenance via feeding tubes attached directly to their stomachs. Children with cerebral palsy and severe neurological impairments cannot swallow and therefore depend upon special prescription formula.

These cuts are part of a broader attempt by the state to sharply curtail Medicaid spending, including plans currently underway to privatize Medicaid services. Florida is viewed as a model for those seeking to dismantle the Medicaid entitlement program for the poor and elderly throughout the United States.

The Miami Herald reported March 12 that officials at the state Agency for Health Care Administration (AHCA) have denied that the changes were motivated by cost cutting; however, an e-mail obtained by the paper last week from an AHCA director stated the contrary. "We've made many policies more restrictive than in the past, due to the out-of-control costs of Medicaid," the Medicaid program director Emily Fritz explained to a dietitian who had inquired about the cuts. "It was a tough, but necessary, decision," she wrote.

AHCA Secretary Alan Levine, when asked by the *Herald* March 10, insisted that he had not heard of the changes, but offered bland assurances that he would be reviewing the new policies to ensure that no harm came to children. On the day the story ran, Levine issued a statement to Florida legislators declaring that the paper was engaging in sensationalism and that the article was "absolutely not true."

"To be clear," he wrote, "with the exception of experimental procedures, any service determined to be medically necessary for children is approved." He suggested that the doctors themselves were to blame for denial of their patients' requests. "Based on the information I have already been provided with, it appears the problems reported in the story are related to whether the physicians were adequately educated on how to access the prior authorization system." Doctors interviewed by

the *Herald* in a story published March 14 vigorously rejected these accusations.

In fact, the state appears to have been quietly restricting its definition of what it deems "medically necessary" when reimbursing doctors for services provided to Medicaid patients. As the e-mail from Fritz made clear, many similarly "tough" cuts and restrictions have recently been made under the radar. In implementing them, ACHA administrators have taken the decision of what is medically necessary out of the hands of medical practitioners, who are increasingly being told that they will be reimbursed for only the most minimal services.

Care providers who filled out requests for reimbursement for the formula reported being turned away repeatedly in recent months, without explanation or forewarning. Pat Hare, director for children's nutrition at All Children's, which oversees dietary care for children in clinics throughout central Florida, told the *Herald* that no one was even aware of the policy change until the agency's reimbursement forms were returned stamped "denied."

Gwen Wurm, community pediatrics director at the University of Miami, ran into similar problems when her patients' caregivers were being denied en masse. She told the paper that she contacted the state Medicaid office herself to find out how she could fill out the forms on behalf of her patients so that they would be accepted. "They tell you they won't answer questions about it," she said. "I fill out the forms, and they get rejected."

According to other health workers at the University of Miami, Medicaid officials suggested they instruct their patients' care givers to "blenderize" table food and find a way to pour it into patients' gastrostomy tubes—incredibly uninformed and dangerous advice. Not only would it be difficult to puree food to a consistency thin enough to introduce through a G-tube while meeting nutritional requirements, but such a procedure could clog the tube or cause infections, Dr. John Thompson, director of pediatric gastroenterology at the University of Miami School of Medicine, told the *Herald*.

In a second article, on March 14, the paper interviewed another University of Miami doctor whose reimbursement forms had been rejected. Michael Light, who practices at the university's cystic fibrosis center, said that the state refused to subsidize the cost of formula for several of his patients after

deciding that it was not medically necessary. According to Light, only those adults who receive 100 percent of their nutrition and children who receive half theirs through the supplement would continue to be eligible. Those of his patients who are able to eat a little, he said, were cut off. "For people with cystic fibrosis, this doesn't make sense," Light told the *Herald*. "You don't want them to gain 100 percent of their nutrition from a [feeding tube] when they can eat." Some of these patients are losing weight and will likely be hospitalized.

Children with HIV and AIDS also rely on liquid formula as a nutritional supplement in order to suppress an extreme malnutrition associated with the disease called HIV wasting. These children are being denied under the new policy, and Medicaid officials have claimed that there are other ways of feeding them more cheaply.

This latest policy change is staggering in its hypocrisy. In 2003, Florida Governor Jeb Bush drafted a law ordering the reinsertion of a feeding tube into Terri Schiavo, the Florida woman who was kept in a permanent vegetative state for a total of 15 years against all medical advice, her own expressed wishes and those of her husband. The law was passed by the state legislature, but was later overturned in the courts. Governor Bush and the entire Republican and Christian right mobilized to insist her feeding continue. Bush sought to exploit the Schiavo case for reactionary political ends, but it is an entirely different story when it comes to providing care for those who really need it.

In his recent State of the State address, Republican Governor Bush barely alluded to the Medicaid program. What comments he did devote to the subject bore no resemblance to reality. "We've increased funding to serve Floridians with disabilities, to protect children, and to provide community-based care for elders, each by at least 140 percent," he said. "We've also taken the first critical step to create an effective and efficient Medicaid system."

By an "effective and efficient Medicaid system," Bush was referring to the steps that Florida has taken to overhaul the health program in the state. After receiving federal approval last fall, Florida is currently in the process of privatizing its Medicaid program. The plan, crafted by Jeb Bush, will shift the Florida Medicaid program from the traditional "defined benefit" to a "defined contribution" system, in which the state will provide a certain amount that can go toward the purchase of private insurance. The Governor's plan effectively replaces entitlement, need-based aid with finite individual accounts managed by for-profit corporations, which will make the decisions on what treatment to provide and what to charge in copayments and other fees.

Full approval for the new program is still pending in the state legislature, but a pilot program officially begins this July for Medicaid beneficiaries in Broward and Duval counties.

Approximately 210,000 poor and seriously ill or disabled Floridians will be involved in the "test" run this summer. If the

plan is adopted by the legislature, all 2.2 million Medicaid beneficiaries in the state will be shifted to the new program within the next five years. The limited nature of these accounts will have devastating consequences for those suffering from cancer, AIDS, and other terminal or permanent conditions.

At the same time that such restrictions on care and caps on expenditures are being imposed upon beneficiaries, Governor Bush is pushing for \$1.5 billion in additional tax cuts along with the elimination of the taxes on stocks and other intangible items. During his two terms, Bush has overseen \$15 billion in such tax cuts, overwhelmingly for the benefit of the very rich, while picking apart programs for the poor.

Dismantling and privatization are also being pursued at the federal level. When Florida received approval from the US Department of Health and Human Services last October, it was hailed as being a watershed event that was sure to clear the way for privatization throughout the country. Announcing the approval of Governor Bush's proposal, Secretary Mike Leavitt declared it was "a day of transformation" for entitlement programs, adding, "I believe it will be considered a milestone of national leadership."

Medicaid is a program that is run by the states but is jointly funded by both the states and the federal government. At the federal level, billions of dollars worth of Medicaid cuts over the next several years were pushed through as part of President George Bush's 2006 budget, and billions more are targeted in the White House 2007 budget proposal.

Unlike Social Security and Medicare, however, major structural changes in the program must be passed by the states. Over the past several years, nearly every state in the country has taken steps to cut costs by tightening enrollment requirements, restricting care to those below poverty and others in the so-called mandatory group of applicants, and introducing co-pays for medical consultation and prescription drugs.



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