



## The Wilsons: “Forced Poor” to Pay for Care

Amy and Tim Wilson describe themselves as “forced poor.” Their annual income of \$25,000 makes it a constant challenge to support a family of five, but it keeps them eligible for the Medicaid program that covers most of their son Hunter’s ongoing medical expenses. “I would be cutting my own throat to go back to work,” says Amy.

Amy and Tim Wilson moved their family to Little Rock, Arkansas so their son Hunter, 9, could attend the state’s only school for the deaf. An antibody deficiency, however, has since left Hunter unable to attend school at all. A teacher comes to the Wilson home four hours a week.

Amy, an EMT, had to stop working in order to care for Hunter. His frequent hospitalizations and the lack of suitable child care make it impossible for her to maintain employment. “Besides,” she says, “if I did go back to work, Hunter would lose his SSI and Medicaid.” Tim works two jobs to support the family of five, earning \$25,000 a year as an insulation blower by day and a FedEx courier by night.

“We are ‘forced poor,’” says Amy, so that the family doesn’t have too much income for Hunter to qualify for Medicaid. While the state’s TEFRA option would allow the Wilsons to receive Medicaid coverage for Hunter even if their income went up, “you can’t apply for TEFRA until you don’t have Medicaid anymore, which makes it hard to switch without a gap in your child’s coverage.”

Because of lung disease, Hunter uses a ventilator much of the time and a wheelchair when he is having



The Wilson family are forced to live on a miniscule budget so that their son, Hunter, can qualify for Medicaid and get the care he needs.

trouble breathing. He also needs an intrapulmonary percussive ventilator (IPV), pulse oximeter, feeding pump, suction pump and globulin infusion pump. The family's electric bill is \$300 per month, in large part due to Hunter's equipment. Sometimes they skip a car payment to make sure the electric bill is paid.

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While glad to have Medicaid benefits for Hunter, the family can be frustrated by its one-size-fits-all regulations. "Medicaid provides thirty suction catheters per month," says Amy. Hunter doesn't need to be suctioned that often. On the other hand, "he can only get one new hearing aid a year. He is supposed to wear them in both ears, but right now he only has one because he lost one, and it's not time yet to get another one." The move to Little Rock meant leaving behind Amy's mother, a primary part of the family's support system. When Hunter is hospitalized, Tim drives the family's other two children 150 miles to stay with their grandparents so he can keep working and Amy can be with Hunter. The gas costs are significant.

Hunter is occasionally able to eat normally, but most of the time he is fed through a G-tube. "We're actually kind of lucky that way," says Amy. What she means is that, when Hunter is in the hospital, the staff will bring him a meal tray, which he won't touch. Because her son is technically able to swallow but prefers to receive nutrients by tube, Amy gets to eat. She says "lucky" without a trace of irony.

"The times when he can't eat, like before surgery, I just go without," she says. "Or I go to the place down the street and give plasma. They give you \$40 each time, and I can use that to eat."

## Pathways to Financial Hardship for Families of Children and Youth with Special Health Care Needs (CYSHCN)

1. **Higher health care costs:** The Wilsons had to pay \$200 out-of-pocket for a new G-tube when Hunter's broke. Although G-tubes are covered under Hunter's Medicaid plan, coverage is limited to only one per year.
2. **Higher routine expenses:** The family's electric bill is \$300 per month, in large part due to the medical equipment that keeps Hunter alive. When Hunter is hospitalized, the family drives his siblings 150 miles to stay with their grandparents, adding significantly to their gas costs.
3. **Loss of employment income:** Amy, an EMT, had to leave her job to care for Hunter. His frequent hospitalizations and the lack of specialized medical day care make it impossible for her to go back to work. Tim would turn down a pay raise if it meant the additional income would make Hunter ineligible for his SSI and Medicaid benefits.

### Breaking the Link to Financial Hardship for CYSHCN

1. A [Medicaid buy-in program](#) like the one that is part of the federal [Family Opportunity Act](#) would let Tim accept a pay raise without losing Hunter's public health insurance.
2. Specialized [medical day-care](#) might allow Amy to go back to work and bring additional income to the family.
3. [Consumer-directed benefits](#) or a **flexible funding program** would allow the Wilsons to decide how to spend limited resources. They might purchase a new G-tube or hearing aid for Hunter, or use flexible funding to help pay the electric bills rather than getting more suction catheters than they really need.

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## About the Catalyst Center

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