

# Disabled Face Hard Choices As States Slash Medicaid

By [CLARE ANSBERRY](#)

FLORENCE, S.C.—Tandem forces of shrinking state budgets and rising health-care costs have collided and struck a small brick ranch house in this rural town, home to Barbara Hickey.

Born with cerebral palsy, Ms. Hickey, now 67 years old, is confined to a motorized wheelchair. She lives alone and relies on certified nurse's assistants to get her in and out of bed, bathed, clothed and fed.

In December, she received a letter from the South Carolina Department of Special Needs and Disabilities, saying her weekly 50 hours of personal-care help was being cut to 28 hours. That meant Ms. Hickey would get help for two hours in the morning and two hours at night. If she needed to use the bathroom in between, she would sit in a soiled diaper.

After several days of reduced care, the local office of the South Carolina Legal Services appealed the cuts on behalf of Ms. Hickey. Her hours have been restored pending the appeal.

Home health care—funded largely by Medicaid—generally costs less money than institutionalizing developmentally disabled people like Ms. Hickey. But the political reality is that it's easier to cut back home services than to close a 24-hour facility, which can leave people with nowhere to go. Thus, some of the biggest cuts around the country are happening in the basic services that help the disabled cope at home.

South Carolina says it has little choice but to cut funding for Medicaid. It faced a \$563 million deficit for the current fiscal year, and like other states must have a balanced budget. Medicaid, the joint federal-state health-insurance program for the poor and disabled, already consumes about 20% of its \$5 billion budget and is one of its fastest growing costs.

The health-care program is on course to consume 40% of the budget of South Carolina in five years, and leaves little for anything else, says Gov. Mark Sanford. "It could force legislators to either cut further into bone in the areas of education, law enforcement and economic development, or raise taxes. Neither option is palatable."

The state already is making painful cuts elsewhere. The state's Department of Juvenile Justice has closed five group homes and cut 25 after-school programs. There are 1,000 fewer public-education teachers this school year than last.

Across the country, budget-strapped states are focusing on Medicaid. Created in 1965, it is now a \$379 billion program, including state and federal funds. State spending grew an average 7.9% in fiscal 2009 as the economic crisis hit and more people signed up for Medicaid.

It was the highest growth rate since the last downturn six years ago. Spending is expected to keep growing at that pace for the next decade because of rising costs and growing enrollment.

But states don't have much flexibility when it comes to what they can and can't cut inside Medicaid. Although it is a state-managed system, the federal government pays a percentage of each state's total costs and makes many of the Medicaid rules. Under federal Medicaid law, states must offer inpatient and outpatient hospital care, X-rays and lab services. They also have to cover nursing-home services and meet certain standards, such as staffing ratios.

There are further constraints this year. States can't reduce Medicaid eligibility this year because of a condition attached to federal stimulus money, and under health-care reform, they can't eliminate existing programs.

States also run up against other laws when they make deep cuts. Lawsuits have been filed in South Carolina, Florida, Connecticut, Virginia, Mississippi and New York, claiming Medicaid cuts make it impossible for those with disabilities to live at home and that it violates the Americans with Disabilities Act.

Logically, states would cut the most expensive, least efficient services and keep the most cost-effective. But because of mandates and the need to save money quickly, that isn't as easy as it sounds.

For example, home care—because relatives often provide some of the care—is generally cheaper than housing people with developmental disabilities in institutional facilities. In 1993, the average Medicaid cost for each person with disabilities was \$48,500. At the end of 2008, the latest figures available, it cost an average \$55,000. Adjusted for inflation, that actually represents a 23% decrease, largely as a result of more services being shifted away from costly institutions to the home, says Charlie Lakin, director of a University of Minnesota program that tracks services for the developmentally disabled.

But many in-home services, though critical to those receiving them, are optional. Furthermore, there aren't many minimum standards set for in-home services, so it's easier to cut them without violating funding requirements. There are fewer immediate consequences for the state when it cuts those services because families won't generally abandon disabled relatives and leave states on the hook for housing.

Cutting home care could ultimately prove penny-wise and pound-foolish, however. It could push more people into institutions or large group homes because that is where services are guaranteed, even though institutional care is more expensive.

Although only about 10% of the Medicaid budget goes to treat the 618,000 developmentally disabled Americans—the same percentage as a decade ago—average spending for each person is more than 10 times higher than for all Medicaid recipients. "Since their services cost the most per person they draw attention," says Mr. Lakin.

New Mexico has cut cash assistance payments for low-income disabled residents by one-third. Vermont and California have made cuts to home-based programs for the disabled.

Some of the biggest cuts are coming in South Carolina. Tax increases are particularly hard to pass here, so lawmakers rely largely on spending cuts to balance the budget.

Since 2008, the Department of Disabilities and Special Needs has lost 28% of its base funding, eliminated physical, speech and occupational therapies and capped the amount of diapers and nutritional supplements provided to people living at home. Seven group homes were closed.

The department's fiscal problems have been exacerbated by past spending decisions. A special state audit released in December 2008 showed that the department hadn't provided many new services for which it had received funding and, as a result, it couldn't recoup millions in federal matching Medicaid dollars. For example, the state spent less than \$700,000 of \$10 million allocated to serve autistic children, which resulted in the loss of \$13.6 million in federal matching money. The state said it couldn't ramp up the program fast enough because it couldn't find qualified service providers. After the audit, the executive director of the department and four of the department's seven commissioners resigned. The department has since implemented most of the recommendations made by the Legislative Audit Council.

Recent state cuts have targeted developmentally disabled people living at home. In December, families were told that some of their in-home support was being cut by as much as half.

Brian Phillips, a 37-year-old with cerebral palsy, was told that he was losing half of his personal-care hours. He can work a TV with a remote control but can't dress or feed himself, or get in and out of his bed or wheelchair.

He lives alone with his father, James, 70. The elder Mr. Phillips, who has had open heart surgery and whose heart functions at only 26% of its capacity, cannot lift Brian on his own. He appealed the cuts and the hours were restored pending his appeal.

"These are cuts no one wants to make. They are very difficult for agencies to implement and they are very upsetting and very, very difficult for our families," says Lois Park Mole, spokesperson for the state Department of Disabilities and Special Needs.

People will generally do what they must to keep their disabled family member at home regardless of the cuts. At some point, however, even the most dedicated may not be able to continue, especially as their own health deteriorates.

Jimmy "Chip" Eubanks of Clinton, S.C., has severe cerebral palsy, but doesn't have mental retardation. "My mind works fine," he says. The 37-year-old has a full life at home. He can drive his motorized wheelchair with his mouth and use a computer with a stick-like device attached to his head. During the football season, he writes notes to the Clinton High Red Devils team and prepares plays for them. He hasn't missed a game in 18 years.

"My biggest fear is having to go to an institution," he says.

His parents were able to take care of Chip on their own until about three years ago when Linda Eubanks, now 68, had a brain aneurism. Already diabetic, the aneurism further compromised her health. She is nearly blind and in a wheelchair.

She can't see well enough to drive, use the stove or feed her son. Her husband has a bad back and can't lift Chip, who is 6 feet tall and weighs 185 pounds.

The couple relies on Amber Plaia, a certified nursing assistant. Ms. Plaia gets Chip out of bed, bathes, dresses and feeds him. She takes him to doctors' appointments.

In the evening, Chip's uncle, who lives nearby, can put him into bed most nights. Otherwise, Chip sleeps in his wheelchair.

Chip's personal-care help—essentially Ms. Plaia—has been cut in half to four hours a day. He appealed and his hours were restored pending the appeal. He, and three others, have filed suit against the state, saying the cut violates the Americans with Disabilities Act.

Ms. Park Mole said people like Chip could get "respite care" to help make up for the loss of personal-care help. Medicaid also helps pay for respite care, which costs less because the workers provide a lower level of care.

In some parts of the state, personal-care workers are paid \$12 an hour and respite-care workers about \$8 an hour.

Families said that isn't always a feasible option. Respite-care workers aren't expected to bathe people or clean breathing tubes, and families say it can be hard to find qualified ones.

In Aiken County, Board of Disabilities Executive Director Ralph Courtney says waiting lists for services are growing. There are more than 5,000 on waiting lists for various services, from residential programs to in-home programs.

"We want to give families hope to keep their family unit together, but in reality there is very little we can put in place to assist them," says Mr. Courtney.

In-home support is cheaper, he says, than the alternative: group homes and larger residential programs that need to be maintained and staffed 24 hours a day. "But you can't put people out on the street," he says. "You can cut in-home support."

Even though Ms. Hickey lives alone and needs help with nearly every aspect of daily living, it cost less to have her live in a house with 50 hours of personal care help than in a nursing home. Institutional care in South Carolina costs about \$100,000 per person a year, compared to \$39,000 for home and community services, according to the University of Minnesota research.

There are other considerations. Though disabled since birth, and barely able to read or write, Ms. Hickey is aware of her surroundings and her situation.

She enjoys being able to go outside the back door, which is equipped with an automatic opener, onto a porch. She can ride her motorized wheelchair down the street to Burger King. She doesn't want to live in a nursing home, institution or group home. "I'm not losing my mind. I just don't have a body to do things other people can," she says.

The cuts for the developmentally disabled are almost certain to bite deeper in the future. Part of the federal stimulus money this year was designed to prop up Medicaid. The federal infusion disappears for the fiscal year starting in July 2011.

South Carolina faces an even bigger budget deficit of \$1.1 billion when the one-time money runs out.