



PHOTOS BY MIKE MORONES / THE FREE LANCE-STAR

Amy Fields stretches her daughter Cary Lynn's feet while she undergoes breathing therapy.

Cost cutting falls on 'the most fragile'

BY CATHY DYSON
THE FREE LANCE-STAR

The sign on the door tells visitors they're at the home of a medically fragile child and would they please wash their hands, remove their shoes and use sanitizer upon entering—or not enter at all if they're sick or have been around someone who is.

"We appreciate your help in keeping our sweet girl healthy and germ-free," reads the Welcome sign at the Louisa County home.

Parents Amy and Shannon Fields are trying to keep 7-year-old Cary Lynn stable. They adopted the girl when she was 9 months old—just a "little butter bean"—her mom recalled, and she was about to be put in an in-

stitution because no one wanted to undertake her lifetime of care.

One glance changed everything.

"She opened her eyes and looked at us," the mother said,

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GLITCHES CAUSE PAY DELAY FOR ATTENDANTS

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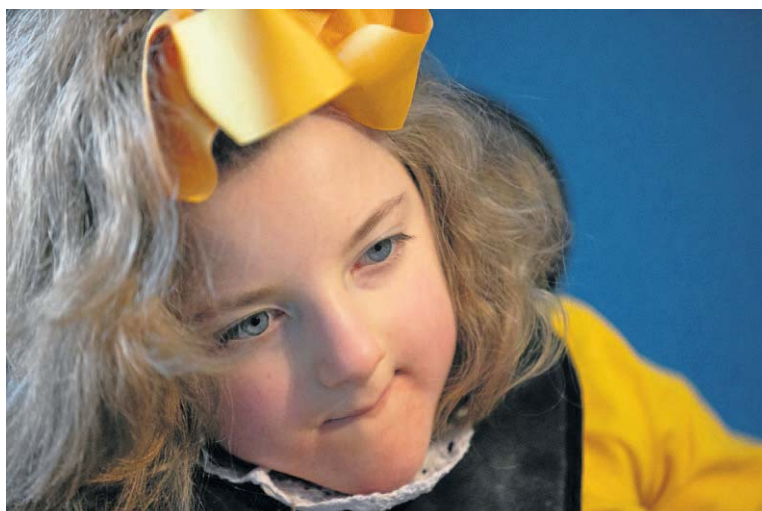
At least three local elected officials are working with the state on an additional glitch with Medicaid that has left providers unpaid for weeks—or months—at a time.

"This is impacting so many families statewide," said King George County Supervisor Ruby Brabo. She's working with Stafford County Supervisor Meg Bohmke, state Sen. Richard Stuart, R-Stafford, and the National Association of Counties on the matter.

Brabo and Stuart got involved when Lisa Pitts of King George County went two months without a paycheck. She's the personal care attendant for her son, Hunter Pitts, a 26-year-old who suffered a brain injury eight years ago.

Lisa Pitts said she filed necessary paperwork, but didn't get paid in January or February. She went through several layers of bureaucracy

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Cary Lynn Fields, 7, was born with a variety of disabilities and requires full-time care that is covered through Medicaid waivers.

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“and we felt like she fit in our family.”

Since then, Amy Fields has become her daughter's caregiver, with help from personal care attendants paid for by Medicaid. Cary Lynn and Marvin, 11, who asked for a “baby scissor,” both receive Medicaid as all children adopted through Virginia agencies do. Their father, Shannon Fields, works in information technology for a supermarket chain based in Mechanicsville.

Cary Lynn has “about a bajillion things going on,” her mother said, including cerebral palsy that's taken away all body movement, fluid on the brain, visual impairment and mitochondrial disease. Her needs are so severe, she qualifies for placement in a nursing home.

Yet as a result of recent changes, the amount of time Medicaid will pay attendants to help with her care has dropped from 80 hours to 49 hours a week. Similar reductions are happening statewide as the Virginia Department of Medical Assistance Services, which administers Medicaid, tries to cut costs.

“A physician who has never laid eyes on my child made this decision, and I'm just one of many this is happening to,” Amy Fields said. “Between the eternal waiver wait list, reduction of hours and lack of support, we truly are in a lose-lose situation.”

SENDING SHOCK WAVES

Medicaid waivers pay for services for those who would otherwise be in an institution, nursing home or hospital. The program gives recipients the option of staying with their families or maintaining independence in community homes, said Jennifer Ryan, service facilitator at the disAbility Resource Center in Fredericksburg.

There aren't figures available on the difference in costs between keeping a medically fragile child at home versus institutional fees, but comparisons for senior citizens shed some perspective.

Nationwide, it costs \$82,128 to \$92,376 a year for nursing-home care, according to the website seniorliving.org. Paying health-care aides to come to the person's home and help with daily activities is considerably less, averaging \$59,040 annually.

In Virginia, 37,671 people get eight different types of Medicaid waivers, and news of cuts in attendant hours is sending shock waves through the “waiver community,” said King George County resident Lisa Pitts.

Her son, Hunter, has been disabled since suffering a traumatic brain injury in a motorbike crash eight years ago.

Lisa Pitts quit her teaching job to take care of her son, and the money Medicaid pays her to be his attendant has gone to therapies, trainers and treatments not covered by insurance. Hunter Pitts is 26 and needs constant su-



Lisa Pitts helps her son Hunter, who has a brain injury, move from the car into their home in King George.

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LENGTHY WAITS

An anecdote from Mary Lou Nissim-Sabat, a home health care nurse in Spotsylvania County, illustrates the way the Medicaid process has changed.

When she started working with Medicaid patients 12 years ago, the agency focused on keeping people out of nursing homes. If

a stroke victim needed a hospital bed and wheelchair at home, she'd fax the doctor's order to a medical supply company, and the equipment would be delivered in two days. She recently had a similar case—and it took 11 months and rounds of lost paperwork and authorizations to get the equipment.

APPEALS AND ADVOCACY

The disAbility Resource Center will address the denials and delays of Medicaid waivers at 10 a.m. March 29 at its Fredericksburg office at 409 Progress St.

The program will include Medicaid's recent changes, how costs have been cut and the roles of facilitators and case managers. The

group also will discuss how recipients can appeal the cuts and join advocacy efforts.

Individual cases will not be addressed. Seating is limited, and registration is encouraged online or by calling 540/373-2559 or 540/373-5820 for captioned telephone.

PAY RATES FOR ATTENDANTS

A personal care attendant, who helps the most severely disabled children and adults with their basic needs, can make \$2.71 more per hour by crossing a county or city line. Medicaid pays attendants \$11.93 per hour

in Fredericksburg, Spotsylvania and Stafford counties and all jurisdictions north because of the areas' higher cost of living. Everywhere else in Virginia, the rate is \$9.22 per hour. Attendants don't get health insurance or any other benefits.

WAIVERS MEET THEIR GOAL

Funding problems with Medicaid waivers don't mean the services themselves aren't working, said Kim Lett, deputy director at the disAbility Resource Center.

She's seen evidence with her own son, Ryan, who's 30 and has significant disabilities. With the waivers, he's been able to live indepen-

dently in a group home, and the purpose of the waivers is to help others do the same—or to be able to stay with their families instead of being institutionalized.

“We truly believe that people really are much happier when they are part of the community and a part of their family,” she said.

persion, like Cary Lynn.

Yet his attendant care has been reduced from 56 hours to 31.5 hours per week because another medical official determined the additional time wasn't necessary. As in the case with Cary Lynn, the doctor never examined Hunter.

No aspect of Hunter's condition has changed. If anything, he's getting worse, his mother said, because she hasn't been able to take him to needed therapies. She almost died from a ruptured spleen in 2017 and is still dealing with complications.

‘PICKING ON’ THIS GROUP

All this is happening as Virginia works to enroll an estimated 400,000 uninsured people as part of the Medicaid expansion. One seemingly doesn't have anything to do with the other, but Lisa Pitts has to wonder.

“How are they going to pay for that?” she asked. “On the backs of the severe and profound that

they just shoved off? It feels like they're picking on this population.”

A policy change did impact waivers for some recipients under age 21, said Christina Nuckols, media relations manager for DMAS, the agency that administers Medicaid. DMAS is working with the Centers for Medicare and Medicaid to resolve the matter.

Nuckols said her agency has been sharing information with families so young patients can get the services they need. But she said the policy change affected only those under 21 through the Early and Period Screening Diagnosis and Treatment waiver, or EPSDT.

She didn't have an answer for why recipients such as 26-year-old Hunter Pitts had his care hours reduced.

‘WERE WE ALL WRONG’

Medicaid has always been a difficult system to navigate. Things got even trickier in 2017 when

Virginia joined others nationwide in having its Medicaid waivers program operated by private health-insurance companies.

Recipients and their families “were all told not to panic and that things would not change that much,” Amy Fields said. “Boy, were we all wrong.”

The private companies are known as MCOs, or managed care organizations, and workers in Virginia's six companies performed additional evaluations when they took over the system.

In many cases, waiver recipients were told they no longer were eligible for some services they'd had in the past, said Lucy Beadnell, a director for The Arc of Northern Virginia, which advocates for people with developmental and intellectual disabilities.

“Read between the lines, and this is a cost-cutting measure,” she said. It affects “the most fragile in our Medicaid system.”

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with the managed care organization that oversees her son's care.

If her case manager told her the necessary papers had been filed, the health care agency would say it never received them.

“So I'm caught in the middle, going back and forth, with both of them screaming at me,” she said. “Then it becomes, ‘We got 400 faxes in one day, and we don't know whose came and whose didn't.’”

“I don't give a crap whose fault it is, just fix it. I need to get paid.”

Her family won't go in the poorhouse without the income as her husband, Al, works at the Navy base in Dahlgren. But when their son got hurt, Lisa Pitts quit her job as a teacher so she could take care of him, and the money she receives through his Medicaid waiver helps pay for his therapies.

The disAbility Resource Center of Fredericksburg has helped a lot of clients with similar payment problems, said Jennifer Ryan, service facilitator.

“One attendant did not get paid for five weeks,” she said. “I couldn't go without my check for five weeks.”

Lucy Beadnell, advocacy director for The Arc of Northern Virginia, also has dealt with “lots of people whose care hours went unpaid” for long periods. Even worse than the delay is the fact no one's accountable, she said.

“There's no repercussions for that, no one responsible when these care attendants making \$20,000 can't pay their mortgages,” Beadnell said.

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Amy Fields holds her daughter Cary Lynn, 7, at her home in Bumpass.

The MCOs had to hire thousands of employees to act as facilitators and case workers for Medicaid clients, Beadnell said, and some staffers don't have much experience with patients who will need services for the rest of their lives.

“They're not into the long-term care side of things; they don't understand what that means,” said Tinnie Gratz, a Medicaid specialist with the disAbility Resource Center. “They're still on the medical model.”

That means the workers know all about processing prescriptions and medical care, Gratz said, but not about daily life for those who can't take care of themselves.

These patients “would starve to death if they didn't have somebody feeding them,” she said.

Or without supervision, they're at risk for choking or other hazards. Ryan has one client who technically can feed himself, but he's been known to chew on anything he can get his hands on, even batteries.

IMPOSSIBLE TO KEEP UP

Amy Fields believes a person reviewed her case and assumed her daughter doesn't need personal attendants during school hours. But Cary Lynn doesn't go to school anymore. When she did, she kept getting exposed to germs—and getting sicker—and her mother decided “it's not realistic for her to be in school.”

But it was realistic for the mother to support

the family income by doing transcription work at home while an aide cared for Cary Lynn. That isn't possible if the mother is working full time on giving Cary Lynn therapies to keep her from developing pneumonia or doing stretching exercises to flex her spastic hands and feet.

Likewise, Lisa Pitts wondered if a clinician reviewing her son's case simply marked items off a checklist. If a client can put a fork in his mouth or slip on a shoe, does that mean he doesn't need help with the tasks?

Lisa Duggan, the King George physician assistant who's taken care of Hunter Pitts for years, stressed in a letter that he's completely dependent on an attendant for all aspects of personal care.

“He cannot do any of these tasks without supervision or assistance,” she wrote.

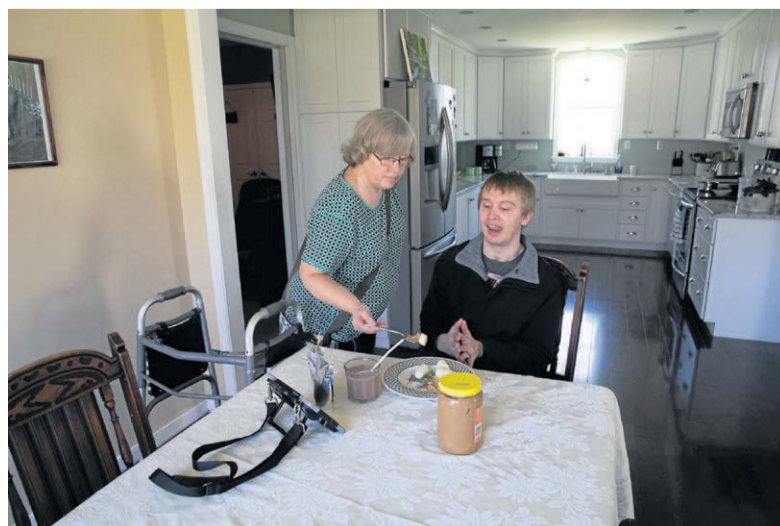
The cuts are the latest change in what seems like an ever-growing list: a redesign of the waiver system, move to managed care organizations, expanding Medicaid and changes to the organizational structure as part of a Department of Justice settlement, all in the last three calendar years.

“All of these pieces were moving simultaneously, which makes it all the more complicated,” Beadnell said. “There are so many changes, it's almost impossible for families to keep up.”

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Medicaid has reduced the amount it will pay for Cary Lynn's care.



Lisa Pitts helps her son Hunter with lunch at their home.