

'This Is Their Only Option'

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HARRISONBURG — Steven Utterback has been waiting for help for 14 years.

The 32-year-old Rockingham County resident is one of 133 people with an intellectual or developmental disability in Harrisonburg and Rockingham County who were waiting for Medicaid assistance waivers at the end of 2015.

The waiver program is designed to help pay for community-based educational and therapeutic services for the disabled.

The programs can range from job training and life skills to in-home nursing assistance. In some cases, waivers are used to pay the costs of placing the person in an assisted-living facility or state institution.

Statewide, the waiting list for waivers stands at 10,356 individuals and families.

Utterback's parents, Ken and Sue, said their son was placed on the waiver waiting list when he turned 18.

"He doesn't have anything," said Ken Utterback.

Steven receives Social Security benefits, but cannot have more than \$2,000 in assets.

"His uncle wanted to leave [Steven] everything in his will, and we had to ask him not to, because he'd lose his benefits," Sue Utterback said.

According to Ken Utterback, the family had applied to open a "special needs trust" to set money aside for Steven's care, but the application was denied, leaving them dependent on being granted a waiver.

For the Utterbacks, their only option is to care for Steven out of their home. But like many parents with disabled children, they know they won't be able to care for him indefinitely.

Sue Utterback said the family has two other adult children, who are also concerned about Steven's future.

"They're wondering if they have to stay in Virginia and help care for him, but they have their own lives and families," she said. "We're in our 60s. When is there going to be a time when we can stop worrying?"

'Only Doing The Minimum'

According to Jamie Liban, executive director of advocacy group The Arc of Virginia, the structure of the waiver program has been a concern for years, but lawmakers have done little to address it.

Liban says the waitlist for services is growing steadily, in part because of a 2011 finding by the U.S. Department of Justice.

The department declared Virginia wasn't doing enough to help people with intellectual or developmental disabilities live independently in society.

The ruling came after the department toured many of the state's training centers, where intellectually or developmentally disabled people had been housed. Federal employees found little to no evidence that residents were interacting with people outside the facility, nor that they were receiving any instruction in basic life skills.

The department ruled that Virginia must transition the facilities' residents to community-based support services, increasing the backup of waiver applications as families struggled to find care for their loved ones.

Another issue is the way the waitlist is prioritized.

"The Virginia system tends to be crisis-driven," Liban said. "Under this system, you have to be someone with aging caregivers or whose caregivers just died to get services."

She said that forced many people with disabilities into a state hospital because the lack of community-based programs means they never learned the skills necessary to live independently. It also bumps people with less urgent needs further down the list.

The number of available waivers is proposed each year in the state budget, and, according to The Arc, only 365 waiver slots were available at the beginning of the fiscal year in July.

In a typical year, Liban said, fewer than 800 people are granted waivers.

"The state, right now, is only doing the minimum to comply with the DOJ," she said, "but if the General Assembly doesn't do something soon, the waitlist will keep growing."

A Common Situation

Steven attends programs at The Arc of Harrisonburg and Rockingham twice a week, where he learns job skills and is able to socialize.

Heather Denman, executive director of the branch, said the Utterbacks' story is pretty typical.

"Often, we see people who have no way to pay for support and services, so we secure funding from other agencies and we fundraise to cover the costs," she said. "For a lot of people, this is their only option, so we have to do something."

James Ward, president of the board for the Harrisonburg and Rockingham chapter, said many families also are never told what services are available in the community.

When he and his wife were looking for assistance for their 12-year-old daughter, Ella Schminkey-Ward, they didn't know where to start.

"A lot of people just said, 'Oh, Medicaid will pay for that,' like they assumed she was automatically enrolled," Ward said.

Ward said many parents go through the same struggle, with little to no guidance navigating the state and federal systems to get help for their child.

"It's difficult enough when you don't know what's happening to your child," he said, "but to add this maze on top of it. ... I don't know what kind of words to put it in."

Budget Amendment

Two Valley lawmakers are leading the charge to amend the state's budget and provide more waiver slots to families on the waiting list.

Del. Steve Landes, R-Weyers Cave, and Sen. Emmett Hanger, R-Mount Solon, are joining with Del. Kirk Cox, R-Colonial Heights, to sponsor budget amendments increasing the amount of available waivers from 800 to 5,000 a year.

Landes said he's increasingly heard from struggling families stuck on the waitlist, and has been working on similar amendments for a few years.

"When you listen to the families and the individuals that are waiting, it's clear the waivers really help provide the services they need," he said.

The state also is looking to restructure the waiver program, breaking them into multiple categories, based on the level of care required.

"With the system now, you get a waiver and you get all of the services," Landes said, "but maybe you don't need all of those services. This will help tailor waivers more closely to what the recipients need."

Waivers are paid out of the state's general fund. Because many recipients are institutionalized, waivers cost an average of \$36,000 per person.

Under the amendments, however, more waivers would be used to pay for in-home, supplemental care, causing the average cost of a waiver to drop to \$16,000 a person.

Liban said modifying the program makes sense, in more ways than one.

"It's good policy," she said, "both fiscally and for human lives."

Landes said he's seen the impact the programs can have firsthand.

"I have friends and family members who have children with intellectual or developmental disabilities," he said. "I know how much these programs help."

He also noted this is the first time both the House and the Senate are working to address the ever-growing waiting list.

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- Caption: Ella Schminkey-Ward, 12, of Harrisonburg, the daughter of James Ward and Donna Schminkey, looks at books Wednesday afternoon at The Arc of Harrisonburg and Rockingham. (Photos by Nikki Fox) Steven Utterback, 32, the son of Ken and Sue Utterback of Rockingham County, uses an iPad Wednesday at The Arc of Harrisonburg and Rockingham.

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