

Missouri creates new fund to provide assistance for the disabled

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[Buy this photo](#) A man with down syndrome cooking.

For nearly 22 years Karen Bradbury has worked to keep her autistic son Derrick safe, supervised and cared for because his disability makes it difficult for him to hold a job, speak appropriately to others and take care of himself.

But at 53, the St. Charles mother worries about the future. She knows she's not going to be able to keep up with the constant supervision and coaching her son needs to thrive as she and her husband age. She fears that one day, Derrick, 21, will have no choice but to reside in an institution away from his family and without the chance to work and contribute to his community.

"We don't want him to just sponge off the government. We want him to have a job and make a difference and feel good about himself," she said.

The Bradburys, like some 4,500 other Missouri families coping with developmental disabilities, need outside help that they cannot afford. The family had been languishing on a state waiting list for funding for a personal assistant for their son.

On Friday that waiting list vanished for Bradbury, and the future suddenly looks brighter.

In an era of severe budget cuts, Missouri has scraped together \$8.2 million in new local, state and federal Medicaid funding for an estimated 480 families who needed services to keep their loved ones at home and active in society instead of in costly institutional care.

Until now, almost all assistance funding administered by the Missouri Department of Mental Health had routinely bypassed these families and gone to those facing homelessness or other severe crises — usually caused by the loss of a main caregiver.

In the St. Louis region, nearly 2,000 families are on the waiting list for financial waivers to pay for basic services such as job training, transportation and behavioral therapy.

For families on that list, the situation is frustrating. Bradbury said that without the financial assistance, her son probably would not get the behavioral coaching he needs to learn to live independently. That would one day lead to a crisis when she could no longer care for him. Only then — when it was a traumatic emergency — would he get the funding.

"Derrick has to learn to take direction and be around other people besides us, because my husband and I will not always be here," Bradbury said.

The new program began signing up families last week in 37 counties. In the St. Louis area, participating counties include St. Charles and Lincoln and the city of St. Louis, which collectively contributed \$420,000 to the fund through their disabilities boards. The brunt of the local funding is coming from a \$300,000 allocation from St. Louis and \$100,000 from St. Charles County.

About 40 new families are expected to be served in St. Charles County and even more in St. Louis.

St. Louis County, which has a tax levy to help fund prevention services through its disabilities board, chose not to participate because the majority of its residents do not qualify for the Medicaid waiver, said Joyce Prage, executive director of St. Louis County's Productive Living Board.

The extended funding came about after the Missouri Association of County Developmental Disability Services studied other states for a model. Officials with the state Department of Mental Health then redirected \$1.5 million in assistance money to preventive service requests, and asked county and city mental health boards around the state to collectively match it. That \$3 million secured \$5.2 million in federal funding from the Centers for Medicare and Medicare Services to encourage home-based care rather than institutional settings that can cost taxpayers more than \$200 a day.

The assistance program is modest relative to the number of families in Missouri still in need of preventive services, and the benefit is capped at \$12,000 a family. However, state officials said the investment is a start.

The fund will enable the Bradburys to hire a personal assistant for about 50 hours a week, said Peg Capo, executive director of the Developmental Disabilities Board of St. Charles County.

Derrick will get intensive behavioral coaching when he is working and carrying out daily tasks.

This could prepare him to live in a supervised apartment or group home.

"He's the perfect person for a program like this," Capo said. "It will give his family a break and give him the extra time to motivate him. He'll be able to get out in the community fully."

Bradbury said her son loves animals and has a gentle way with dogs, but he was recently laid off from his beloved job at a pet day care. With a personal assistant, Bradbury believes Derrick will find and succeed at a similar job. She was so concerned about him languishing at home, she said, that she considered accompanying him to a new job at another kennel to coach him through the workday — an exhausting proposition.

State and county officials said the new funding is expected to give caregivers like Bradbury a needed breather so they don't burn out. Studies show divorce rates are high among families coping with a disability. The deterioration of family support further jeopardizes the individual with the disability, said Kathy Meath, CEO of St. Louis Arc.

"They need this prevention waiver because it's going to help families stay together," she said.