

Need disability help in Kansas? Thousands wait an average of seven years

By [Alex Smith](#), HEARTLAND HEALTH MONITOR | **October 13, 2016** [Kaiser Health Network]

At his apartment in Olathe, 42-year-old Nick Fugate catches up on washing dishes and remembers the 22 years he spent doing that at a local hotel, trying to stay on top of a never-ending stream of plates, glasses and silverware.

Nick recalled minor annoyances like the long days, the hot kitchen and his fingers pruning in the water. It could be tedious, but he said he didn't really mind.

"Just as long as I got the job done, it was fine," Nick said.

The job wasn't glamorous, but Nick's father Ron Fugate said it was the key to the self-reliance he wanted for his son since Nick was born with an intellectual disability.

"From our perspective, having a job, being independent, participating in the community, paying taxes, being a good citizen — that's a dream parents have for their children in general," Ron said.

But all of that changed last year when Nick lost his job and did something he'd never done before: He enrolled in Medicaid.

That landed him in a state of limbo, along with thousands of other Kansans with intellectual and developmental disabilities.

Savings up in smoke

Not far from Nick's home, 30-year-old David Lee Hunter and a handful of men at Lakemary Center in Olathe take apart computers and other electronics for recycling.

Hunter thinks of each piece that passes across his workbench as a unique puzzle.

"I like to improvise, and I like to ask my co-workers for assistance," Hunter said.

Elsewhere in the building, other individuals with disabilities shred medical documents or get job coaching. Lakemary also offers services like transportation or help buying groceries.

A few decades ago, many of Lakemary's clients might have received Medicaid care as residents of an institution. But in the early 1980s, states began shifting their strategies to allow people with intellectual and developmental disabilities to live at home.

Advocates said this was not only much cheaper — about a third of the cost of institutional care — but it provided a vast improvement in the clients’ quality of life.

In many states, however, the first step toward getting these services is signing on to a long **waiting list**.

That’s what happened when Nick applied for Medicaid. In the months since, he’s had to pay around \$1,000 a month out of pocket for Lakemary’s services.

It’s quickly burning through his life savings.

Like many Kansans in similar situations, the Fugates have been speaking out about the waiting list and other Medicaid problems at public forums like one in May in Kansas City, Kan.

Waiting for improvement

In a basement meeting room of the Jack Reardon Convention Center, hundreds of people with disabilities, their families and caseworkers railed against KanCare. Some even heckled the moderator.

The [state has been gathering feedback](#) because it needs federal government permission to continue running KanCare, Kansas’ privatized Medicaid program.

In 2013 Republican Gov. Sam Brownback put Medicaid under the management of three private insurance companies, [promising managed care](#) would improve services, cut waste and save enough money to end the lists for the kind of services Nick Fugate needs.

But families of Kansans with developmental disability didn’t trust the companies to [provide the complicated help](#) their loved ones needed. They managed to get the federal government to delay the switchover, but in February 2014 federal officials gave their approval and the KanCare experiment began for them.

More than two years later, many families say they’ve seen few signs of improvement, particularly in the waiting list.

Not only is there [still a waiting list](#), it has grown by a few hundred to about 3,500 people.

Except in emergency situations, the average wait is seven years.

Complicated cases

An end to the list remains in view, according to Brandt Haehn, commissioner for home and community-based services in the Kansas Department for Aging and Disability Services.

“I think everybody in the system is doing the best job they can do to provide the people services,” Haehn said.

In August, the department announced it had [eliminated a different waiting list](#): the one for physical disability services.

Although that claim has been challenged by advocates, state officials said it shows KanCare can get results.

Haehn, however, acknowledges that developmental disability cases are more expensive and complicated, and it will take time to come up with the state’s share of the total cost of \$2.6 billion — about \$1.5 billion — needed to eliminate the waiting list through 2025.

“Nothing would make me happier than to write a check and give all these people services, but that’s just not reality,” Haehn said. “So I have to deal with what reality is and try to use the money that I have to effect positive change in the most amount of people.”

Still waiting

Ron Fugate thinks KanCare had its chance.

“We’re not treading water; we’re drowning,” Fugate said. “And it’s not getting any better. We’ve got to start taking some serious action on this and get it addressed. We’ve kicked the can down the road too long.”

The Department of Justice is [investigating the waiting lists](#), although it declined to comment for this story.

The state’s ability to act may be limited. Brownback’s tax cuts, which were supposed to boost the economy, have blown a huge hole in the state’s budget, leaving little money to apply to something like a Medicaid waiting list.

Meanwhile, Nick Fugate is still waiting.

His parents are in their 70s, and they say they’re now watching their carefully laid plans for their son’s future slip away.

“After 22 years, it looked like he was going to be able to complete a career, and it didn’t happen that way. And so all of this comes at a time in our lives where we’re in the waning seasons of our life, and we did not anticipate this kind of a challenge at this point.”