



More than 3,000 on waiting list for developmental disability services

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By



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Kelly Ware, who was born with Prader-Willi syndrome, is one of more than 3,172 people on the state waiting list for services for people with developmental disabilities.

Anna Claire Statum loves her cats, Kitty and Smoky, the television station Nick Jr. and giving her mother "I want" demands such as "I want Coca-Cola," and then "I want ice water," after her request for sugary soda gets turned down.

But at 26, Stanton, who was born with profound developmental disabilities because of a recessive gene, can't live independently. Her parents, Carl and Susan, are in their mid-sixties and worry about what will happen to their daughter as they age. They'd also like her to have a place she could go during the day "where recreational activities are encouraged, to have some company."

"It's a conundrum. There is no good ending," said her mother, Susan Statum.

Statum, of West End, said her daughter has been on a state waiting list for home and community-based services for more than 10 years.

There are 3,172 people on the waiting list for community services, mostly for residential services such as group homes but also day programs and other services, according to the Department of Mental Health. About one-third of the people are already receiving some services while they wait for others, but 1915 have no services.

Advocates said the list is continuing to grow, leaving families waiting for years and often not getting to the top of the list until there is a emergency such as the death of a caregiver.

"Our state could choose to fund these services. To this point we have chosen not to," said James Tucker, an attorney with Alabama Disabilities Advocacy Program.

"This is a choice that our state is making to not serve 3,100 people that they have determined need those services," Tucker said.

The slots are provided through Medicaid waivers, paid through a combination of federal and state funds, and aimed at helping people with disabilities meet their living and educational needs.

Department of Mental Health spokesman Jeff Shackelford said the problem is money.

"We're helping people as fast as we can with the funds we have available," Shackelford said.

"The tough financial times we're facing do not make this any easier," he said.

The state's General Fund budget has been hit by proration for the past several years, causing additional reductions in funding for non-education agencies.

Department officials acknowledged the list has continued to grow. Last year, the department was able to get services for 139 people on the list, but another 505 people were added to it, according to department officials.

"The number one thing people can do is call their lawmakers and ask them to give us more money. The more money we have, the more people we can help on this list," Shackelford said.

Sen. Arthur Orr, R-Decatur, who chairs the Senate committee that oversees the General Fund, said the state budgets are "extremely stressed." He said the Department of Mental Health has taken "great strides to reduce the cost structure," including continuing to move people from institutions to community settings.

"Those cost savings should translate to additional funds to help, not solve, the backlog," Orr said.

Alabama in 2011 ranked 46th among the 50 states in spending on services for developmental disabilities per \$1,000 of statewide personal income, according to annual data collected by Professor David L. Braddock and the Coleman Institute and Department of Psychiatry at the University of Colorado. The state ranked 44th in 2009, according to Braddock.

"The financial support for the effort is anemic," Braddock said.

Advocates for both people with disabilities and mental illnesses have praised Alabama's efforts to move people out of institutions and into community settings, following court decisions that say people should be cared for in the least restrictive setting possible.

Alabama is one of only a handful of "lofty" states that operate no institutions for people with developmental disabilities, Braddock said. The state closed its last remaining institution last year and moved residents to group homes or other community settings.

Most consumers are now cared for in community settings, Shackelford said.

"The Alabama Department of Mental Health is committed to helping our consumers with the best care possible. We are working diligently to help as many people as possible," Shackelford said.

But Braddock said the need hasn't been fully addressed on the other end -- helping people who already were living at home but need some services.

With limited funds, the state has to triage people on the waiting list. They are ranked according to "criticality of need."

A person being well-cared for at home such as by their parents is not in immediate need, Shackelford said. But as their situation changes -- such as a change in their financial situation or the death of a caregiver -- they move up in priority, Shackelford said.

"It's not like a waiting list of the doctor's office where it's first come, first serve," Shackelford said.

While advocates say it's unrealistic to think the state could ever eliminate the waiting list, they argue it could do better.

Cinque Johnson, 29, was born with Down Syndrome, and his mother had cared for him at her home in Ensley. But she died in June from pancreatic cancer. His sister, Zakiya Gwinn, has been on leave from her job as a child protective services worker in Maryland to care for him ever since.

Gwinn said her mother tried to update his criticality rating after she was diagnosed with terminal cancer and had hoped get him into a group home.

"There is no place for my bother to go. I basically have to lie and say I don't want him anymore. They said the only way he would qualify for emergency services is if he was homeless," Gwinn said.

"The waiting list is too long. It seems as if Alabama does not care," Gwinn said.

Gwinn said she has considered taking her brother to Maryland, but she said she fears starting at the bottom of another state's waiting list.

The Robinson family in Chambers County said their daughter, Kelly Ware, 33, brings much happiness to their lives, but they'd like to get a little help enriching her life.

Mary Ann Robinson said she knew in her gut something was wrong with her daughter before they left the maternity ward. She never cried. She was floppy. She couldn't suck at her bottle. Her worries were largely dismissed first as "failure to thrive" and then "just slow."

It wasn't until Ware was four that, during a medical visit for Robinson's son, another doctor turned and asked, "What's wrong with her?"

The diagnosis came back as Prader-Willi syndrome, a rare genetic disorder.

Ware, who was signed up for services in 2009, was offered a slot in a day facility two years ago, but Robinson said they turned it down because they didn't feel it was appropriate. The facility had ready access to food, and Robinson said people with Prader-Willi syndrome have an insatiable appetite coupled with difficulty processing food.

"She just can't be around where there is food," Robinson said.

Robinson said their case worker has assured her she'll be able to find a place for Ware if something should happen to them, but she said she'd like to get some help for her daughter sooner.

"I just get so frustrated," she said.

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