

Graduating to waiting



Juliet Banks is pictured here with her son, Brandon.

Students with disabilities age out of public schools and land on a waiting list

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Juliet Banks wants the same things most mothers want for their children.

She wants to see her son reach his potential and achieve at least some of his dreams, including working and moving away from home. But 21-year-old Brandon is somewhere in a 4,000-person deep line waiting for services offered to people with developmental disabilities.

Banks, who attended his final days at Highland Park High School last month, is among a growing number

of Kansans who at 21 have aged out of the public school system to find nothing waiting on the other end. It is a difficult reality for those with disabilities who can find themselves going from the classroom to the couch, and it is a logistical challenge for families that must make difficult decisions about how to care for children that can't be left home alone. They are decisions that can lead some families to leave jobs, sending them into a financial tailspin.

"It is one of the, I think, dirty little secrets out there," said Rocky Nichols, executive director of the Disability Rights Center of Kansas. "These families who have fought so hard to get special education and related services for their children and fought so hard with Medicaid to get the services and support they need when they are under 21 now get sucker-punched and not only run up against a brick wall, they run into a brick wall, bounce off of it and then find themselves standing in a line called a waiting list that is 4,000 deep."

For a time, Banks helped other families with disabled children navigate the system. In those years, the waiting list was manageable. Still, years in advance, she put her son's name down, requesting that services begin when he turned 18. But when funding didn't keep up with demand, Brandon stayed in school until he was 21 — the age at which students with special needs age out of public schools. He is still waiting.

"My husband and I will probably have to cut back on work during the day," Juliet Banks said.

Services vary depending on the need of the recipient. They could include around-the-clock care, assistance to live independently with roommates or support for working in a job. Some families are able to pick up the tab for the care — at least for a short time, said Ramona Macek, community developmental disabilities organization director at TARC. Some families face crisis, particularly one-income, single-parent homes. When they are available and able, grandparents can be invaluable, she said.

The Banks are among the families that can count themselves lucky to have two wage earners.

"There are families that have it a lot worse than I do," Juliet Banks said.

Some help is coming, but advocates say it won't be enough. The Legislature restored a 10 percent cut in Medicaid funding that affected both the pay for workers in the field and the quantity of services provided. Lawmakers also added \$6.9 million that will be shared to address the waiting list for the physically and developmentally disabled. Tom Laing, executive director of InterHab called the new money a "drop in the bucket" that might take 150 names off the waiting list.

Lawmakers, Laing said, have years of underfunding to address. Although he said it feels like

lawmakers turned a corner this year toward addressing funding, "a hell of a lot of people were ignored."

"It's terribly shortsighted," he said. "The responsibility has been passed on from legislative session to legislative session until the current Legislature was faced with a multiyear challenge. It will take us three or four years at a minimum to whittle down the waiting list until it's manageable again."

In the meantime, many of those children will stay in school longer. Anecdotally, school districts like Shawnee Heights Unified School District 450 say they are seeing greater numbers of children with developmental disabilities stick around until age 21 rather than leave at 18 because they are on the waiting list.

Of Shawnee County residents waiting for services, 81 are between the ages of 18 and 21, Macek said. Some, she said, have waited five years for services.

It is a waste, Laing said, to invest in intensive education services while children make their way through public schools and then leave them with nothing on the other end to help them maximize their abilities.

"When you deny them the one path that exists for them to do that you've not only stolen from their lives but you've thrown your money into the fire, so to speak," he said.

The options are limited. Tonia Martin's oldest son Justin White recently finished up at Washburn Rural High School. While Justin is 21, Tonia Martin can't leave him unsupervised. Cooking would be dangerous. He likely wouldn't make a good choice if a stranger came to the door. As is, Justin receives 15 hours of support services during which he works one day and volunteers another.

Martin believes her son is near the top of the waiting list but is planning to spend time at home with Justin in coming months. A recent graduate in social work from Washburn University, she is going to take some time off before returning to school to work on her master's degree. Until he finds his way off the waiting list, she worries he will lose out on the future he had envisioned, including living away from home.

"Everything we planned for and hoped for, now that his time has come, we're uncertain of what is going to happen," she said. "It's not fair to them. They deserve the same opportunities that we have."

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