

Family awaits help



Photo by [Dave Ranney](#)

Leslie Debrabander uses gumballs to coax her daughter, Abby, 10, into sitting still long enough to have her picture taken. Abby is developmentally disabled. The Debrabander family has applied for Medicaid-funded in-home services designed to help them keep Abby in their home rather than placing her in a state hospital. They've been on the program's waiting list for about five years. They've been told not to expect respite care services for at least two more years. "It's frustrating," Debrabander said.

By [Dave Ranney](#)

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OLATHE — About five years ago, Leslie Debrabander invited a woman from Johnson County Developmental Services to her home to talk about the possibility of getting services for her daughter.

Abby Debrabander, then age 5, has multiple physical and developmental disabilities.

"We talked about Abby and the services she would need and what was available," Debrabander said. "When we were through I asked her when she thought we'd get started and she said it would probably be seven or seven and a half years. I couldn't believe it."

Debrabander said she, her husband, or their two daughters, ages 15 and 12, must be with Abby, now 10, at all times.

"If I go in the bedroom like to fold laundry, Abby will go to the pantry get a bag of potato chips and dump the whole thing out," she said. "When I come back she'll either be lining the chips up on the counter one by one or she'll be eating them all."

Another time, she said, Abby inadvertently set her hair on fire.

"It's like that all the time, 24-7," Debrabander said, noting that some nights, Abby will sleep for only two or three hours.

“When she doesn’t get much sleep, it means I don’t get much sleep,” Debrabander said. “We have alarms on all the windows and doors.”

Abby can walk and is able to feed herself but she has trouble speaking. She’s not yet toilet trained.

“She’s fearless,” Debrabander said. “When we take her to the playground someone has to be within arm’s length of her at all times. She’ll do stuff the other kids know not to do.”

The Debrabanders are one of about 1,074 Kansans families on the state’s waiting list for Medicaid-funded services for children with developmental disabilities. About 1,200 adults with developmental disabilities also are waiting for services.

“I don’t understand this,” Debrabander said. “I mean, I know the state is short of money but they had money five years ago and they didn’t fund the services back then either. It’s like they’ve pushed kids like Abby to the side. It’s like they don’t matter. It’s frustrating.”

Debrabander, 43, said her family isn’t asking for much.

“I know there are families who have more needs than we do,” she said. “But if we could just get someone to come in during the summer and supervise Abby and help her learn the skills she needs that would be great.”

Debrabander said during the school year Abby is in class during the day and is “pretty worn down” by evening.

“We can handle that,” she said. “It’s those six to eight weeks when they don’t have school in the summer that things get really crazy around here.”

Debrabander said she and her husband have considered hiring a specially trained babysitter during the summer.

“They want like \$10 an hour,” she said, “and there’s no way we can afford that.”

Debrabander said she’s tired of hearing legislators promise to reduce the waiting list but then balk at appropriating the funding.

“I challenge each and every one of them to spend a week in my shoes,” she said. “And Abby’s easy. A lot of parents have it much worse than we do.”