



'Best' Places to Live With Autism All in Major Metro Areas: Survey

Even so, three-fourths of families polled nationwide said they had difficulty accessing needed services

By Jenifer Goodwin

HealthDay Reporter

WEDNESDAY, April 13 (HealthDay News) -- After their 4-year-old daughter was diagnosed with autism last December, Kristen Paurus and her husband, Bill, sought out doctors and therapists who could help.

In their hometown of Sebeka, Minn., population 710, that's not easy.

The closest speech therapist is 40 minutes away, a drive their daughter, Brea, makes with her dad twice a week. It's a three-hour trip to Children's Hospitals and Clinics of Minnesota in Minneapolis, where Brea sees a neurologist, gastroenterologist, urologist and a behavioral pediatrician.

Kristen wants her daughter to see a behavior therapist, but the nearest one is two hours away. A representative from a statewide autism organization said it might be able to send a behavior therapist to her rural area, but two months later, she still doesn't have an appointment.

"It's so hard not being able to provide something for your daughter that could possibly help her so much," Kristen said.

The Pauruses are far from alone. About 1 in 110 U.S. children -- and 1 in 70 boys -- has autism, and its prevalence is increasing.

Yet, nearly three-fourths of about 850 parents of children with an autism spectrum disorder surveyed by Autism Speaks said they're unable to access needed medical, educational or recreational services.

Based on the results of the online survey, Autism Speaks listed the best places for families with an autistic child to live. Parents in 10 major metropolitan areas -- New York, Los Angeles, Chicago, Cleveland, Philadelphia, Boston, northern New Jersey, Minneapolis/St. Paul, Seattle and Milwaukee -- tended to report better access to services.

"Many parents are telling us they have to drive too far, there are not enough services and it's too difficult to get the services even when they exist close by," said Mark Roithmayr, president of Autism Speaks, a New York City-based advocacy organization that funds autism research.

But among those who reported having difficulty, 67 percent said they regularly drive an hour or more for services.

Five of the 10 "best places" to live are in states that have enacted autism insurance reform that requires insurers to cover screening, diagnosis and treatment for people with autism. Overall, about half of states have enacted reforms, while others have legislation pending, according to Autism Speaks.

Besides reporting a lack of services, a majority of respondents (83 percent) said they had difficulty finding "appropriate" recreational activities, such as programs for kids with special needs.

Another challenge for families with an autistic child is balancing work with caregiving. Only about 55 percent said their employers had flexible policies that enable them to work and take care of their child.

"If you have a child or a teen with autism, often their needs consume almost every moment of your waking hours," Roithmayr said. "We have had so many instances in which the mom or dad has had to quit a job to stay at home to make sure the coordination of services is happening and that the child's needs were being met."

That's the decision the Pauruses made. Bill stopped working to care for Brea and their 2-year-old daughter, while Kristen kept her job, in large part because it offers good health insurance, which they need to pay for Brea's treatment, she said.

"This is affecting corporate America in huge ways, but corporate America has not addressed this yet," Roithmayr said. "A really good or family-friendly employer would understand that when you have a child with autism, at any moment of any day, you may have to be out of the office attending to his or her needs."

Despite the stress that can come from constant caregiving, few families said they could get respite care, which offers parents a break to run errands or go out to dinner without their child. Many parents of children with autism can't leave their child with the neighborhood babysitter.

"Respite services are not a luxury, they are a necessary service that allow families to successfully keep a child with autism in the home environment versus institutional care, and increases the overall wellness of all family members," said Patricia Wright, national director of autism services for Easter Seals, in a news release. "Every parent needs a break."

Friends and family can help by getting to know the child and offering to babysit, but more formal programs are needed, Roithmayr said.

Family is the major factor keeping the Paurus family in tiny Sebeka, despite the lack of services. Kristen and Bill grew up there, and both sets of parents, siblings, and plenty of aunts, uncles and cousins live nearby. They pitch in with babysitting, and Brea knows they love and accept her.

But if the behavioral therapist doesn't come through soon, the Pauruses might move to Minneapolis/St. Paul, and perhaps commute home on weekends.

"They say it's good for her to have people that love her and understand her around her," Kristen said. "So what do you do? Do you go somewhere you know nobody and don't have that support? Or do you stay where you are and don't get the professional services you feel you need?"

<http://consumer.healthday.com/Article.asp?AID=651759>

More information

The [U.S. National Institute of Neurological Disorders and Stroke](#) has more on autism.

SOURCES: Kristen Paurus, Sebeka, Minn.; Mark Roithmayr, president, Autism Speaks, New York City; Autism Speaks, news release, April 1, 2011

Last Updated: April 13, 2011

Copyright © 2011 [HealthDay](#). All rights reserved.