

Putting a lifetime cost on autism

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Kristina Rhodes loves helping families with autistic children. But she may have to cut back her hours as an early-intervention therapist because her own autistic son, Erik, 10, isn't thriving in school.

That's a familiar situation for Rhodes, who recalls how she couldn't work at all when her son was younger. "I basically lost income until he went to kindergarten," she said.

And the disorder continues to drain her family's finances. "We can't buy a house that we necessarily want to be in," she said.

The financial burden of caring for a child with [autism](#) was underscored recently in a study published in *JAMA Pediatrics*. The average lifetime cost of supporting someone with autism in the United States is \$ 1.4 million, the study found. For those with autism and an intellectual disability or cognitive impairment, the expense rises to \$ 2.4 million.

"The cost is just a number, but it's a big number," said David Mandell, the study's principal investigator and director of the Center for Mental Health Policy and Services Research at the University of Pennsylvania.

Mandell studies community care and services for those with autism, which affects about one in 68 children in the United States. People with autism have difficulty with social interaction and communicating with others and often display repetitive behavior, such as lining up objects.

Mandell's study claims to be the most comprehensive assessment of costs

to date. Estimates from the last 10 years were lower but far less accurate, Mandell said, but he and his colleagues had to use them as a basis.

"There aren't data to capture all these costs. We were left extrapolating from a small number of studies that exist," he said.

As the Rhodeses know, the study identified the loss of parental income as a major contributor to costs. While one parent stays home from work, medical and therapy costs continue to add up.

"It's very challenging. One parent is often dropping out of the workplace right when these out-of-pocket expenses are starting to hit," Mandell said.

Roberta Bellamy, CEO of the support group West Philadelphia Parents of Autistic Children, has seen parents undergo these struggles.

"I know there's a big gap in the services they need, and they can't afford them," she said. "It's a catch-22."

Bellamy's son Kareem, 16, has autism, and her group is working to provide after-school programs and a summer camp for autistic adolescents.

As autistic teenagers enter adulthood, they often have difficulty finding jobs, leading to their own lost income. Also, costly accommodations such as group homes are often recommended for autistic adults, but may be needed only for the most severe cases. This generalized approach represents a failure of society to provide other options, Mandell said.

The study, funded by the advocacy group Autism Speaks and the Steve Shirley Foundation, also compared costs between the U. S. and the United Kingdom. Total lifespan costs were similar between the two

countries despite differences in health systems. But the breakdown of costs differed: The U.S. tends to spend more on medical services while the U.K. invests more in accommodations.

"It was surprising to see that the costs were so similar between the countries," Mandell said.

He hopes this study will lead to more comprehensive care, including better after-school programs and workplaces that are more flexible for parents.

"We need more efficient and more effective care that is more consonant with the values of our society," he said.

Erik Rhodes is academically advanced for his age, but he struggles with anxiety. Being in gym class or sitting in a crowded cafeteria is challenging. He often misses school because of the stress, so his mother is looking into other schooling options, such as a charter school or a Web-based cyber school.

Erik has a mind for science and is passionate about oceanography, but everyday skills, such as opening a plastic bag or tying his shoes, are difficult. So "we're trying to find a school that is the best fit for him," his mother said.

Although a good insurance plan has kept medical and therapy expenses from becoming too burdensome, reducing her hours would mean serious [costs](#) for Rhodes. Also, getting access to new research-based care that Erik needs, such as reflex therapy and therapeutic listening, can be expensive. Families are often left figuring out alternative options and sharing ideas.

"We're a community within ourselves," said Bellamy.

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