

Households with kids with autism likely to earn less

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New research suggests that the average household with children with autism not only spends thousands of dollars toward educational, behavioral and health care expenses each year, but also suffers from a lesser-known cost that hits them up front – a sizeable chunk of missed household income, perhaps as much as \$6,200 annually.

The study, published in April's edition of *Pediatrics*, paints a more detailed financial picture of how expensive life can become for parents of children with an autism spectrum disorder.

“To our knowledge, this is the first U.S. study that examines this front half of the ‘money in, money out’ equation,” said economist Guillermo Montes, Ph.D., the study's lead author and a senior researcher at the Children's Institute, a not-for-profit organization affiliated with the University of Rochester, where he also serves as a faculty member in the division of General Pediatrics. “To collect data on expenses is fairly straightforward– it's a survey report. But projecting earning potential and then stacking that against actual income requires complex statistical modeling.”

The study is based on data from the National Household Education Survey on After School Programs and Activities in 2005, a telephone questionnaire that drew on parents of more than 11,000 children, kindergarten-age through eighth grade. Parents reported if their child had an autism spectrum disorder, or ASD (that is, if he or she had ever been diagnosed with autism or a pervasive developmental disorder), their

total household income and their highest level of education. Several other demographic details were collected, including the parent's age, type of family (two parent or otherwise) and whether they lived in an urban or rural locale.

These data were then analyzed with a statistical model that predicted, on average, a family's earning potential.

To validate the model's predictive power, researchers first used it to project the average income potential for households without children on the autism spectrum. This estimate was then compared to their average actual reported earnings. The model was within a 0.1 percent error, thus providing reasonable accuracy.

"We were able to forecast within \$80 of what these households, on average, were actually earning," Montes said.

When the demographic and educational characteristics of families with children with ASD were analyzed, their average actual reported annual income fell short of the average predicted income by more than \$6,200.

"That's a staggering 14 percent loss," Montes said. "We presume this may be strongly related to a lack of appropriate community-based support resources and services. This shortage can ultimately overwhelm parents, sometimes forcing them to sacrifice work and income opportunities for the sake of balancing their unique family obligations."

This echoes findings from another nationally representative study Montes led in 2006: Fathers of autistic children were 9 percent less likely to report full-time employment compared to fathers of the non-autistic population.

"The ripple effect, of course, is that this may be impoverishing some

ASD-affected families in the long term. Less savings and less investment make it more difficult to retire comfortably or send children to college,” Montes said.

The next step, he said, is to carry out additional qualitative surveys, interviewing parents to see if their children’s needs are actually impacting their employment decisions.

“Of course, there may be alternative explanations. As more research probes possible genetic links for autism, perhaps we’ll see that the disorder might, to a degree, run in families. That might affect a parent’s employment and income status even more directly than we assume at present. There may also be other barriers to employment that we haven’t considered,” Montes said.

Regardless of the reason, the burden to families is significant. Data collected from 1999 to 2000 showed that each year U.S. taxpayer dollars collectively pay \$12,773 of the annual education expenses associated with each child with autism. In spite of this assistance, ASD-affected families still bore the brunt of the financial burden. Between un-actualized income (again, estimated near \$6,200) and extensive out-of-pocket ASD-related expenditures – one 2006 national study from the University of Rochester estimated that these families paid nearly \$5,300 more than other families – this direct-to-family cost may exceed \$11,000 each year.

“More assessment is needed, but in the meantime it’s sensible for health care providers to ask families about financial difficulties and, whenever possible, assist them in accessing the resources they need,” Montes said.

Source: University of Rochester

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