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Association of Childhood Autism Spectrum Disorders and Loss of Family Income

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What's Known on This Subject

Families of children diagnosed with an autism spectrum disorder spend \$5272 more in health care services than other families. In addition, families of children with autism spectrum disorder face higher expenses for behavioral and educational treatments than other families.

What This Study Adds

Childhood autism is associated with a loss of annual household income of \$6200 or 14% of their reported income. This places a significant burden on families who face additional out-of-pocket expenses with smaller incomes.

ABSTRACT

BACKGROUND. Parents of children with autism have significant out-of-pocket expenditures related to their child's care. The impact of having a child with autism on household income is not known.

OBJECTIVE. The purpose of this work was to estimate the loss of household income associated with childhood autism using a nationally representative sample.

METHODS. Parents of 11 684 children enrolled in kindergarten to eighth grade were surveyed by the National Household Education Survey-After School Programs and Activities in 2005. An autism spectrum disorder was defined as an affirmative response to the questions, "has a health professional told you that [child] has any of the following disabilities? 1) autism? 2) pervasive developmental disorder or PDD?" There were 131 children with autism spectrum disorder in the sample and 2775 children with other disabilities. We used ordinal logistic regression analyses to estimate the expected income of families of children with autism given their education level and demographic characteristics and compared the expected income with their reported income.

RESULTS. Both having a child with autism spectrum disorder and having a child with other disabilities were associated with decreased odds of living in a higher income household after controlling for parental education, type of family, parental age, location of the household, and minority ethnicity. The average loss of annual income associated with having a child with autism spectrum disorder was \$6200 or 14% of their reported income.

CONCLUSION. Childhood autism is associated with a substantial loss of annual household income. This likely places a significant burden on families in the face of additional out-of-pocket expenditures.

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Key Words

autism, household income, pervasive developmental disorder, national survey, economics, National Household Education Survey, United States

Abbreviations

ASD—autism spectrum disorder
PDD—pervasive developmental disorder
NCES—National Center for Education Statistics
NHES—National Household Education Survey
CI—confidence interval
OR—odds ratio

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AUTISM SPECTRUM DISORDERS (ASDs) are pervasive developmental disorders that are characterized by limited verbal and nonverbal communication, social reciprocity, and restrictive and repetitive behaviors. ASD include autism, Asperger's syndrome, and pervasive developmental disorder (PDD). The impact of childhood autism on the familial economy is presumed to be large. On the expenditure side, the literature reports both expenditures paid by parents and by taxpayers. In 1999–2000, taxpayers in the United States spent \$12 773 on service expenditures associated with education for a child with autism.¹ A pilot study based on a small sample of children with autism in the United Kingdom² reported substantial out-of-pocket educational expenditures paid by parents. Out-of-pocket expenditures for educational and behavioral supports by parents of children with ASD have not been quantified in the United States; however private-pay tutoring, private schooling, speech or occupational therapy, and similar expensive services are commonly used. In addition to educational and behavioral services, families with children with autism spend more in health care services than other families. Using nationally representative samples from the Medical Expenditure Panel and the National Hospital Ambulatory Medical Care Survey, 1 recent study³ estimated that parents of children with ASD spend \$5272 more in health care services than other families. Other studies^{4,5} have shown that health care expenditures are substantially higher for children with ASD, as well as for children with disabilities in general. We know far less about the impact of childhood autism on the income side of the familial

economy. The British pilot study² reported a median weekly loss of income of £250. There are no studies estimating loss of income associated with childhood autism in the United States.

Our objective in this study was to estimate the average loss of household income associated with childhood autism in the United States using a nationally representative sample. We used a proportional odds ordinal logistic model to estimate the loss of income attributable to having a child with ASD by modeling expected income values based on parental education and demographic characteristics of families of children with ASD and comparing results with the income these families reported.

METHODS

Sample

The National Household Education Survey (NHES)-After School Programs and Activities Survey 2005 is a nationally representative random-digit dial telephone survey of households with children enrolled in kindergarten through eighth grade who were ≤ 15 years of age. This survey was developed by the National Center for Education Statistics (NCES) to measure participation in after-school programming.⁶ It is part of the NHESs, which have been conducted biannually in the United States since 1991. The survey interviewed parents of children aged 5 to 15 years between January and April 2005. The respondent was the adult in the household most knowledgeable about the sampled child's care and education, typically the mother. The response rate for the After School Programs and Activities Survey was 84.1%.⁶ Weights were provided to adjust for the complex survey design and for nonresponse rates. Thus, the estimates presented in this article are nationally representative estimates.

Measures

ASD Measures

Parents were asked to respond to the questions, "has a health professional told you that [child] has any of the following disabilities? 1) autism? 2) pervasive developmental disorder or PDD?" We defined ASD as any affirmative response to these questions with parents indicating autism, PDD, or both autism and PDD.

Household INCOME

We measured household income using a 14-category ordinal question, "what was the total income of all persons in your household over the past year, including salaries or other earnings, interest, retirement, and so on for all household members?" Categories 1 to 10 classify the household income at \$5000 intervals from 0 to \$50 000, category 11 has a \$10 000 spread (from \$50 001 to \$60 000), category 12 has a \$15 000 spread (from \$60 001 to \$75 000), category 13 has a \$25 000 spread (from \$75 001 to \$100 000), and category 14 is censored (over \$100 000). To calculate estimates of lost income, we calculated the midpoint of each category and conservatively set the last category midpoint at \$101 000, thus censoring the

right tail of the income distribution and eliminating the influence of outliers. Median estimates of income loss were not used, because they are exogenously determined by the spread of the categories of the income question.

Other Disabilities

Parents were asked if their child had any of the following conditions: "a specific learning disability," "mental retardation," "speech or language delay," "serious emotional disturbance," "deafness or another hearing impairment," "blindness or another visual impairment," "an orthopedic impairment," "attention deficit disorder, ADD or [attention-deficit/hyperactivity disorder] ADHD," and "other health impairment lasting 6 months or more." Children whose parents reported to have any of these conditions and did not have ASD were classified in the other disability group.

Demographic Information

The average age of parents was calculated by the mean of the maternal and paternal ages for 2-parent households and the age of the mother or father for single-parent households. Type of family was measured with a dichotomous variable separating 2-parent families from all of the other family types.

NCES provided a derived variable that, "indicates the highest level of education for the subject child's parents or nonparent guardian who reside in the household."⁷ The variable has 5 categories: (1) less than a high school diploma, (2) high school graduate or equivalent, (3) vocational or technical college or some college education, (4) college graduate, and (5) graduate or professional school.

We used the race of the child as a proxy variable for the minority status of the parents, because information on race of the parent was not collected in the survey. We dichotomized the race variable to reflect minority ethnicity, which included black, Asian or Pacific Islander, all other nonwhite races, multiple races, and all Hispanic children of any race.

All of the participants provided informed consent for the survey. Additional information on the survey and informed consent procedures is available.⁶

Weights

We used Stata (Stata Corp, College Station, TX) to adjust for the complex sample design using Taylor approximations that provide the correct standard errors, following NCES guidelines.⁶

Econometric Analysis

The econometric analysis required several steps. First, we tested the proportional odds assumption. We then estimated the proportional odds ordinal logistic model on household income using average parent age, type of family, race (based on the race of the child), level of parent education, urban or rural living area, ASD status, and other disability status as independent variables. The ordinal logistic model is appropriate because household income was measured with a 14-category ordinal variable with unequal spreads (10 categories at \$5000 and 5

TABLE 1 Selected Demographic Characteristics Associated With Household Income

Variable	Nondisabled Children		Child With Other Disability		Child With ASD	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Parent education, $F = 5.03; P < .0001$						
Less than high school	673	7.1	232	7.8 ^a	13	9.3
High school degree or equivalent	2032	24.6	728	28.7 ^a	35	30.1
Some college	2382	27.7	867	31.4 ^a	34	25.1
College graduate	1949	22.0	497	17.5 ^a	25	18.0
Graduate degree	1742	18.5	451	14.6 ^a	24	17.4
Living in urban area, $F = 5.12; P < .01$						
Rural	1358	20.0	489	23.8 ^a	13	15.2
Urban	7420	80.0	2286	76.2 ^a	118	84.8
Race of child, $F = 1.85; P > .05$						
White, non-Hispanic	5016	57.3	1655	59.8	71	53.2
Minority ethnicity	3762	42.7	1120	40.2	60	46.9
Type of family, $F = 13.24; P < .01$						
2-parent family	6498	73.3	1870	66.7 ^a	83	68.2
Other types	2280	26.7	905	33.3 ^a	48	31.8

Race of child used a proxy for minority ethnicity of parent(s).

^a $P < .01$ in comparison with nondisabled children.

categories higher than \$5000). The model estimated 13 simultaneous logistic regressions imposing the restriction that odds ratios for independent variables be the same (proportional odds assumption). The model was then used to predict the probability of falling into each of the 14 income categories for any value of the independent variables. Using the income category midpoints and the estimated probabilities for each category, we calculated average household income based on a censored income measure at \$101 000.

Next, we validated the model by estimating the average censored income for the average person in the sample (all independent variables at their average level) and comparing it with the average reported income in the sample. We calculated the average values of the independent variables for households with a child with ASD and other disability. Using these values, we estimated the expected income of these households given their education level and demographic characteristics absent ASD or disability. We then compared these estimates of expected income with their reported income. The difference between estimated expected values and reported values was the loss of income associated with having a child with ASD or other disability.

RESULTS

Children With ASD or Other Disabilities

There were 59 children with autism in the sample, 41 with PDD, and 31 children with both diagnoses reported. Thus, there were 131 children with an ASD for a population prevalence of 1.06% (95% confidence interval [CI]: 0.84–1.29). There were 2775 children with other disabilities in the data set constituting 23.7% of the population (95% CI: 22.6–24.8). There were 8778 children without any disabilities based on the NHES measures.

Median Household Income

The median income for the sample was \$47 500, and the mean censored income was \$53 254. The median income for the US households in 2005 was \$46 326 according to the US Census Bureau.⁸

Household Characteristics

Table 1 describes the demographic characteristics of the sample for nondisabled children, children with other disabilities, and children with ASD. There were no statistically significant differences between the ASD group and any of the other groups, likely in part related to the relatively small sample of children with ASD. However, more children with other disabilities lived in a household with lower parental education level (28.7% high school graduate vs 24.6%) and lived in an urban area (23.8% vs 20.0%) compared with children without disabilities. Children with other disabilities were less likely to live in 2-parent households (68.2% vs 73.3%) than children without disabilities. We found no differences by race. There also were no significant differences by average parent age among the 3 groups of households.

Household Income Econometric Analysis

The data from this sample supported the proportional odds assumption ($F_{48,10180} = 1.27; P > .05$). Table 2 displays the odds ratios (ORs) of the ordinal logit household income model estimated. Having a child with ASD (OR: 0.62; 95% CI: 0.43–0.91) significantly decreased the odds of living in a higher income household after controlling for parental education, type of family, parental age, location of the household, and minority ethnicity. This suggests that families with a child with autism attain lower income than expected based on their educational and demographic characteristics. Similarly, having a child with other disabilities also decreased the odds of living in a higher income house-

TABLE 2 Results of Multivariate Ordinal Logistic Model

Variable	Model	
	OR	95% CI
2-parent family	3.71 ^a	3.24–4.25
Parental education ^b	2.28 ^a	2.17–2.40
Household in urban area	1.44 ^a	1.26–1.65
Child is white, non-Hispanic	1.99 ^a	1.76–2.23
Parental age ^b	1.01	1.00–1.01
Child has ASD	0.62 ^c	0.43–0.91
Child has other disability	0.68 ^a	0.61–0.76

The ordinal logistic model also produced 13 intercepts (omitted). The default case is households with nondisabled children.

^a $P < .01$.

^b Variable was entered as a continuous variable.

^c $P < .05$.

The coefficients of child has ASD and child has other disability were not different from each other ($F = 0.22; P > .05$).

hold (OR: 0.68; 95% CI: 0.61–0.76). A Wald test found no significant differences between households with a child with ASD and households with a child with disabilities ($F = 0.22; P > .05$).

Figure 1 shows the estimated probabilities of falling into each of the 14 income categories for the average person in the sample (all covariates at the average values) for 3 scenarios: having a nondisabled child, having a child with other disability, or having a child with ASD. Given identical education and demographics, the presence of ASD was associated with greater odds of falling into lower income categories compared with households with nondisabled children. The households with children with other disabilities fell between the other 2 groups for each income level. Other factors associated with higher income included 2-parent households (OR: 3.71; 95% CI: 3.24–4.25), urban households (OR: 1.44; 95% CI: 1.26–1.65), more educated households (OR: 2.28; 95% CI: 2.17–2.40), and households with white non-Hispanic children (OR: 1.99; 95% CI: 1.76–2.23). Controlling for other factors, parental age had no significant association with household income.

Model Validation

Table 3 shows that the estimated income for the average person based on the model (\$53 500.45) was within a 0.1% error (\$80.10) of the reported average income of the sample (\$53 420.35). Thus, the model provides reasonable predictions of average income.

Estimated Loss of Income

As shown in Table 3, given the demographic and educational characteristics of parents of children with ASD, we expected them to have an average income of \$51 693.25 if their child had not been disabled. However, these families reported an average income of \$45 486.55. The difference of \$6206.70 constitutes a 14% loss of income associated with having a child with ASD. Families with a child with other disabilities were less educated and more likely to live in rural areas. Given their demographic and educational characteristics, we expected them to have an average income of \$48 573.06

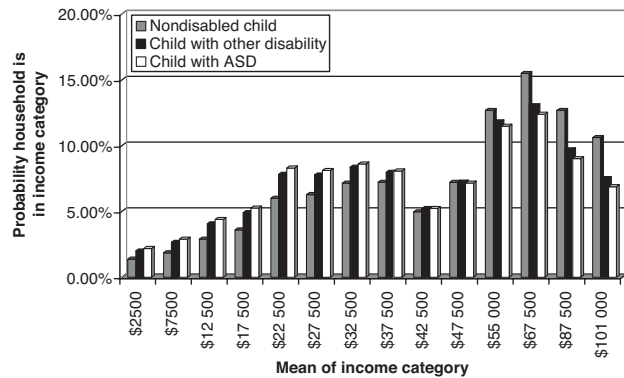


FIGURE 1

Estimated household income for average persons according to the presence of a child with ASD or other disabilities. Note that the midpoint of the more than \$100 000 category was set at \$101 000. The model was evaluated at average values for all covariates except ASD and disability status.

if their child had not been disabled. As a group, they reported an average income of \$47 480.25. The loss of \$1092.81 constitutes a 2% loss of income associated with the presence of a child with other disabilities.

DISCUSSION

To our knowledge, this is the first population-based study estimating the loss of household income associated with having a child with ASD in the United States. We estimate that households with a child with ASD have a substantial loss of annual income of 14% or \$6200. This estimate is based on models created to estimate expected income based on the household's demographic and educational characteristics, and represents the loss associated with having a child with ASD. Given that families of children with ASD face substantial health care expenses,^{3,4} as well as additional educational and behavioral expenses,² the potential economic impact of having lower income in addition to these expenditures is substantial. We found no statistical evidence that families with a child with autism face additional loss of income compared with families of children with other disabilities, although we had a relatively small sample of children with ASD and probably lacked sufficient statistical power. The estimated loss of income for households with children with other disabilities was smaller than for households with a child with ASD, at 2% of their reported income.

Economic theory identifies 3 sources of lower-than-expected household income: (1) poorer-than-expected labor market performance, (2) lower-than-expected labor participation, and (3) lower-than-expected savings and investment, based on parent demographic characteristics and level of education. All 3 of these issues may be true for parents of children with ASD.

Recent research has shown that parents of children with emotional and behavioral disorders lack appropriate community-based services and resources needed to support work and family obligations.⁹ Families with a child with a serious disability often accommodate family and work obligations to the requirements and behavior

TABLE 3 Estimated Loss of Income Associated With Having a Child With ASD

Variable	Annual Household Income (in 2005 \$) ^a		
	All Households (Validation) ^b	Households With Child With Autism ^c	Households With Child With Other Disabilities ^d
Expected based on model	\$53 500.45 ^b	\$51 693.25 ^c	\$48 573.06 ^d
Reported	\$53 420.35	\$45 486.55	\$47 480.25
Loss of income (difference)	\$80.10	\$6206.70	\$1092.81

^a Income distributions censored at \$101 000.

^b Covariates were evaluated at the average values for the sample.

^c Covariates were evaluated at average values for families with children with autism but with no autism present.

^d Covariates were evaluated at average values for families with children with other disabilities but with no disability present.

of the affected child.¹⁰ Lack of resources that fit the special needs of the child can have a significant impact on work and family functioning, leading to significant difficulty in establishing a work-family balance.¹¹ We suspect that this is true for many families of children with autism. For example, in a nationally representative study,¹² fathers of children with autism were less likely to report full-time employment compared with fathers of the nonautistic population and were more likely to work part time. Thus, we speculate that the most likely explanation for loss of annual income in the context of childhood autism is that parents of a child with ASD make different working choices than other parents,¹² perhaps because of the needs associated with ASD combined with the lack of appropriate community-based services and resources.

We also speculate that having a child with ASD likely results in lower savings and investment by families, because of the reported higher medical, educational, and behavioral expenses, resulting in lower interest and dividend income in future periods. There are no studies on the saving behavior of households with a child with ASD or studies of the labor market performance of parents of children with ASD; thus, these speculations merit additional research.

There are alternative explanations for our findings. The association between childhood autism and household income may not represent an indirect cost related to burden of care of a child with ASD but could be the result of other causes. In particular, parental variables related to the broader autism phenotype could be directly associated with unemployment and lower income.^{12,13} In addition, some families with children with ASD may be strategically earning less income to remain eligible for health or other autism treatment-related benefits. Although we consider both of these explanations less likely than the burden of care explanation, they all merit scientific study.

Regardless of the reason for loss of income, however, our findings suggest a significant burden for families.

Limitations of the Study

There are a few potential limitations in this study. Although parent report of ASD is viewed as a fairly reliable,^{14,15} we did not have access to medical charts or diagnostic reports, and we were limited by the way the ASD and income questions were asked in the survey. In

addition, we had a relatively small sample of children with ASD, and, thus, could not investigate additional differences by subgroup. Although the NHES did not ask about Asperger's syndrome, the high prevalence of ASD in the sample suggests that children diagnosed with Asperger's syndrome were included in the autism measure. In addition, we relied on parent report of income, and reporting bias may have been present. Higher income households may be less likely to report a child with disabilities. However, we have no reason to suspect that reporting accuracy would differ for parents of children with autism as compared with other parents.

Implications

Childhood ASDs are associated with a substantial loss of household income. This suggests the need for additional evaluation of available supports for families, as well as specific barriers to optimizing family income. In the meantime, it is prudent for health care providers to ask families of children with autism about financial difficulties and to assist them in obtaining access to appropriate health care, educational services, and community resources.

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