

# Implications of Childhood Autism for Parental Employment and Earnings

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## KEY WORDS

autism, developmental disabilities, family impact, economic burden

## ABBREVIATIONS

ASD—autism spectrum disorders

MEPS—Medical Expenditure Panel Survey

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**WHAT'S KNOWN ON THIS SUBJECT:** Previous research on the cost of childhood autism has been restricted primarily to studying direct costs (money outlays) incurred by publicly and privately funded service systems.



**WHAT THIS STUDY ADDS:** This study estimates the economic impact on the family and examines indirect costs to families in the form of parental labor market productivity losses.

## abstract

**OBJECTIVE:** To examine changes in parental labor force participation, hours of work, and annual earnings associated with childhood autism spectrum disorders (ASD).

**METHODS:** We used the 2002–2008 Medical Expenditure Panel Survey to examine parental labor market outcomes of children with ASD relative to children with another health limitation and children without health limitations. A logit model was used to estimate parental labor force participation. A tobit model was used to estimate parental hours of work and earnings.

**RESULTS:** On average, mothers of children with ASD earn 35% (\$7189) less than the mothers of children with another health limitation and 56% (\$14 755) less than the mothers of children with no health limitation. They are 6% less likely to be employed and work 7 hours less per week, on average, than mothers of children with no health limitation. There were no statistically significant differences in fathers' labor market outcomes across 3 groups. On average, children with ASD are 9% less likely to have both parents working. Family earnings of children with ASD are 21% (\$10 416) less than those of children with another health limitation and 28% (\$17 763) less than those of children with no health limitation. Family weekly hours of work are an average of 5 hours less than those of children with no health limitation.

**CONCLUSIONS:** Families of children with ASD face significant economic burden. Given the substantial health care expenses associated with ASD, the economic impact of having lower income in addition to these expenses is substantial. It is essential to design universal health care and workplace policies that recognize the full impact of autism. *Pediatrics* 2012;129:617–623

Autism spectrum disorders (ASD) are a costly, lifelong set of developmental disorders that affect ~1 in 110 children in the United States.<sup>1,2</sup> The care of children with ASD is often demanding and expensive, imposing extensive costs on families and the education and health care systems.<sup>3–6</sup> In the past decade, the number of children with ASD served in the United States has increased >1000%.<sup>1,2</sup> This rising prevalence of ASD created a sense of urgency for rigorous estimates of costs of ASD, which are critical to appropriate service planning.<sup>7</sup>

Previous research on the costs of ASD has focused mostly on health care expenditures, typically reporting the amounts that providers are reimbursed for services.<sup>1,7–9</sup> A more comprehensive view of costs, however, must go beyond the system-level costs to include the economic impact on the family of the child. The goal of this study is to examine 1 aspect of family economic costs: the burden that results from changes in parental employment associated with raising a child with ASD.

The time required for care of children with ASD combined with the limited availability and high cost of specialized child care may reduce parents' ability to sustain paid employment, resulting in substantial productivity losses for the family.<sup>3–6</sup> Alternatively, parents may increase their workforce participation to pay for additional educational and health resources, thereby incurring costs in the form of forgone home production or leisure time.<sup>10</sup> It has been suggested that the largest component of lifetime costs of ASD is this type of indirect costs.<sup>5</sup> It has been difficult to quantify these costs because of the challenges in collecting the fine-grained data needed for such studies.<sup>7</sup>

The literature on the family costs of caring for children with other disabilities suggests that family economic costs constitute between 5% and 12%

of families' incomes, with indirect costs such as reduced labor force participation, home production, and leisure time representing the majority of these costs.<sup>11</sup> It is not clear whether these estimates are generalizable to families of children with ASD. The economic effects of caring for a child with ASD may be more severe than caring for children with most other disabilities for at least 3 reasons. First, private health care insurance companies frequently severely limit or do not cover autism-specific therapies.<sup>12</sup> Second, children with ASD require intensive health care and education services, which are often provided by multiple providers and thus require more transportation time and general involvement and oversight from caregivers.<sup>3</sup> Third, ASD is often characterized by behavioral challenges that can lead to greater parental labor market disruption.<sup>13</sup> Time-intensive or unpredictable health conditions like ASD are more likely to negatively affect maternal work hours and participation.<sup>13</sup>

The few small published studies of employment outcomes for these families have found that parents are less likely to be employed and more likely to report employment problems such as quitting work, decreasing work hours, or changing jobs because of their child's condition.<sup>14,15</sup> These studies have not estimated a dollar amount associated with the adverse employment events, however. One US-based study, using modeling techniques based on a limited synthesis of previous studies, estimated a lifetime cost of \$3.2 million for a child with ASD, 29% of which comprised parental productivity losses.<sup>5</sup> Another recent study calculated the mean loss of parental income associated with raising a child with ASD to be \$6000 per year, but it did not examine this in the context of labor market outcomes.<sup>16</sup>

In the current study, we estimated the average annual loss of parental earnings

associated with raising a child with autism in the United States. By using a nationally representative sample from the Medical Expenditure Panel Survey (MEPS), we compared labor force participation, hours of work per week, and annual earnings of parents of children with ASD to those of children with another health limitation and children with no reported health limitations. This information is essential in designing public health and workplace policies that recognize the full impact of ASD and appropriately target resources to alleviate its effects.

## METHODS

### Conceptual Model

Having a child with ASD may influence parents' labor supply in various ways. Parents may choose to allocate their time to caring for the child, leading to a reduction in work hours, a change in hours on the current job, a shift from a full-time to a part-time position, or an exit from the labor force altogether. The decision to reduce hours of work or leave the labor force may impose a cost on the family in the form of foregone earnings.

In other cases, parents may increase work hours to earn income needed for supplying services or to secure health insurance coverage for the child with ASD. Family members who have not been in the labor force may enter, move to full-time employment from a part-time position, work overtime, or start a second job. This imposes a cost on the family in the form of the value of foregone home activities and leisure. Market services may have to replace the home activities that were previously produced by the person at home. For example, the family may have to pay for child care to replace care that was formerly provided in the home.

Within a single family, we may observe multiple interrelated labor supply

responses to the burden of ASD. In a 2-parent family, for example, 1 family member may work fewer hours in a paying job and spend more hours in caregiving in the home, and the other may work more hours to compensate for the other's reduced earnings.

### Data Source

We used the MEPS,<sup>17</sup> an ongoing survey of US households that collects detailed information on medical conditions, health service use and expenditures, source of payment, health status, health insurance status, and socioeconomic, demographic, and employment characteristics for each member of the household. A nationally representative sample of households is drawn each year and surveyed 3 times during that year.

The MEPS person-level files include all demographic and medical characteristics, as well as respondent-reported answers to survey questions. The MEPS Medical Conditions file contains a distinct *International Classification of Diseases—Ninth Revision* code for each illness/injury experienced by household members as well as a Clinical Classification Code. By using parent identifiers, we matched children with their parents and assigned parental characteristics to each child.

### Sample

ASD was defined as presence of an *International Classification of Diseases* diagnosis of pervasive developmental disorder (299.X) abstracted from anywhere in the condition file. Because the prevalence of children with ASD is low in each year of the survey, we pooled data across 2002 to 2008 and used sampling weights to adjust for pooled data.

The MEPS also indicates whether a child is limited or prevented in any way in his or her ability to engage in activities that most children of the same age can do. On the basis of this variable, we divided our sample into 3 groups. (1) If children

had an ASD diagnosis abstracted from the condition file, they were assigned to "children with ASD" group. (2) If children did not have an ASD diagnosis but were reported to have any health limitation, they were assigned to "children with another health limitation" group. (3) Children without an ASD diagnosis and children without other health limitations were assigned to "children with no health limitation" group. Our final sample included 261 children with ASD, 2921 children with another health limitation and 64 349 children with no health limitation.

### Variables

Dependent variables included parental labor market outcomes: (1) employment status (employed/not employed), (2) hours of work per week, and (3) annual earnings. The MEPS assesses these variables for each household member aged >16. We estimated labor market outcomes separately for mother and father. Because family economic well-being can be more than the individual employment and earnings of the mother or the father, we also estimated models of family employment (defined as having both parents employed), family hours of work per week (sum of parents' hours of work), and family earnings per year (sum of parents' earnings).

The main independent variable was an indicator of child's ASD status. On the basis of our review of previous research and data availability in the MEPS, we identified a list of variables at the child, parent, and family levels as important covariates.

Child characteristics included age, gender, race/ethnicity (Hispanic, black–non-Hispanic, white–non-Hispanic, other race–non-Hispanic), functional limitation status (presence of a limitation in instrumental activities of daily living or activities in daily living) and rated health score (1 = excellent, 5 = poor).

Parent characteristics included parent's age, years of education and rated health score, and other family income, which is defined as total family income excluding the earnings of the parent.

Family characteristics included family size, family status (2 parent, single parent), number of children in the household, and number of children aged <6 in the household.

Labor market characteristics included region of residence (Northeast, Midwest, West, South) and metropolitan statistical area residence status. Because we pooled data across several years, we included year as a control variable to account for different samples and different employment markets across years.

### Analysis

First, a descriptive analysis of data was conducted. We regressed each variable onto child's ASD status and compared variable means and proportions for children with ASD with those of children with another health limitation and children with no health limitation. Then, for each of the dependent variables, regression equations were estimated controlling for child, parent, family, and labor market characteristics; differences in adjusted means of dependent variables among the 3 groups were compared. The models were estimated separately for mothers and fathers and collectively for the family (whether both parents were employed, sum of parents' hours of work per week, and earnings per year).

A logit model was used to estimate parent's probability of being employed during the year. Marginal effects were obtained from logit regression coefficients. A tobit model was used to account for zero hours of work and earnings in estimation of parental weekly hours of work and annual earnings. Tobit regression coefficients represent the marginal effects of included

variables on parental hours of work/annual earnings.

## RESULTS

### Sample Description

Table 1 presents sample characteristics of each group. Compared with the other 2 groups, children with ASD were more likely to be male, white–non-Hispanic and limited in activities of daily living or instrumental activities in daily living, and less likely to be black–non-Hispanic. They were older on average

and less likely to be Hispanic than children with no health limitation. Children with ASD had better health than children with another health limitation and worse health than children with no health limitation.

On average, families of children with ASD had fewer children than the other 2 groups. They also had fewer children aged <6 years than families with children with no health limitation. Children with ASD were more likely to live in two-parent households than children with another health limitation.

Both mothers and fathers of children with ASD were older and more educated than parents of the other 2 groups. Both parents of children with ASD reported worse health for themselves than did parents of children with no health limitation. Other family income of fathers of children with ASD was less than those of children with no health limitation.

The bottom panel of Table 1 shows sample means (unadjusted) of parental labor market outcomes for each group. We look at the parental labor market outcomes by first presenting unadjusted mean differences, followed by adjusted mean differences. Unadjusted mean differences are presented in Table 1. Adjusted mean differences obtained after controlling for covariates are presented in Table 2.

### Parental Labor Force Participation

Approximately 67% of children with ASD had working mothers. There were no differences in maternal labor force participation among the 3 groups in our sample. Column 1 of Table 2 presents estimated marginal effects obtained from logit regression coefficients, which represent adjusted mean differences in parental employment likelihood of children with another health limitation and children with no health limitation, compared with children with ASD. Mothers of children with no health limitation are, on average, 6% more likely to be employed than mothers of children with ASD.

Approximately 92% of children with ASD had working fathers in our sample. Neither unadjusted analysis nor adjusted analysis shows a difference in father's labor force participation across the 3 groups.

Approximately 56% of children with ASD had both parents working. This was 15% less than that of children with no health limitation. In adjusted analysis, children with ASD are 9% less likely to have both parents working than children with no health limitation.

**TABLE 1** Comparison of Children With and Without ASD<sup>a</sup>

	ASD, (n = 261)	OtherHealth Limitation, (n = 2921)	No HealthLimitation, (n = 64 349)
<b>Child characteristics</b>			
Age	10.45	10.34	8.82 <sup>b</sup>
Male, %	87	57 <sup>b</sup>	0.51 <sup>b</sup>
Hispanic, %	13	15	0.20 <sup>b</sup>
Black–non-Hispanic, %	9	17 <sup>b</sup>	0.14 <sup>b</sup>
White–non-Hispanic, %	74	66 <sup>b</sup>	0.62 <sup>b</sup>
Has limitation in ADLs/IADLs, %	20	04 <sup>b</sup>	0.00 <sup>b</sup>
Rated health	2.26	2.44 <sup>b</sup>	1.68 <sup>b</sup>
<b>Family characteristics</b>			
Family size	4.22	4.29	4.40
Two-parent household, %	76	63 <sup>b</sup>	74
Number of children	2.04	2.32 <sup>b</sup>	2.33 <sup>b</sup>
Number of children aged <6	0.42	0.54	0.73 <sup>b</sup>
<b>Labor market characteristics</b>			
Lives in MSA, %	86	81	84
Lives in Northeast, %	21	18	17
Lives in Midwest, %	21	23	22
Lives in West, %	25	23	24
<b>Parent characteristics</b>			
Mother's age	40.77	38.31 <sup>b</sup>	36.75 <sup>b</sup>
Mother's education	14.06	12.93 <sup>b</sup>	13.03 <sup>b</sup>
Mother's rated health	2.58	2.64	2.20 <sup>b</sup>
Family income other than mother's earnings, \$	48 000	43 000	47 000
Father's age	43.92	41.02 <sup>b</sup>	39.68 <sup>b</sup>
Father's education	13.98	13.06 <sup>b</sup>	13.11 <sup>b</sup>
Father's rated health	2.33	2.42	2.11 <sup>b</sup>
Family income other than fathers' earnings, \$	27 000	31 000	34 000 <sup>b</sup>
<b>Parent labor market outcomes</b>			
Mother employed, %	67	68	74
Mother's hours of work/wk	22.74	23.30	25.80
Mother's earnings/yr, \$	20 479	20 811	26 400 <sup>b</sup>
Father employed, %	92	92	96
Father's hours of work/wk	42.41	41.11	42.81
Father's earnings/y, \$	46 382	45 772	49 158
Family (both parents) employed, %	56	61	69 <sup>b</sup>
Family hours of work/wk	52.27	45.44 <sup>b</sup>	54.09
Family earnings/y, \$	57 100	50 721	63 612

ADL, activities of daily living; IADLs, instrumental activities of daily living; MSA, metropolitan statistical area.

<sup>a</sup> Bivariate regressions were estimated for each variable to compare children with ASD to children with another health limitation and children with no health limitation.

<sup>b</sup> Variable values are found to be significantly different ( $P < .05$ ) from variable values for children with ASD.

**TABLE 2** Estimated Effects of ASD Status

	I. Parental Employment <sup>a</sup>			II. Parental Work Hours <sup>b</sup>			III. Parental Earnings <sup>c</sup>		
	Mother	Father	Family	Mother	Father	Family	Mother	Father	Family
Child has another health limitation	1.75% <i>P</i> = .31	−0.95% <i>P</i> = .73	3.52% <i>P</i> = .23	1.87 <i>P</i> = .43	−1.47 <i>P</i> = .45	−0.65 <i>P</i> = .80	7189 <sup>d</sup> <i>P</i> = .03	6125 <i>P</i> = .14	10 416 <sup>d</sup> <i>P</i> < .001
Child has no health limitation	5.64% <sup>d</sup> <i>P</i> < .001	2.68% <i>P</i> = .34	9.02% <sup>d</sup> <i>P</i> < .001	6.55 <sup>d</sup> <i>P</i> < .001	−0.32 <i>P</i> = .87	5.15 <sup>d</sup> <i>P</i> = .04	14 755 <sup>d</sup> <i>P</i> < .001	7858 <i>P</i> = .06	17 763 <sup>d</sup> <i>P</i> < .001
Child has ASD	ref.	ref.	ref.	ref.	ref.	ref.	ref.	ref.	ref.

ref., reference group.

<sup>a</sup> Logit model is used to estimate dependent variables of whether the child's mother is employed, whether the child's father is employed, or whether both parents employed. Marginal effects are reported. All regressions include parent's age, education, rated health, an indicator of 2-parent household, number of children, number of children aged <6, family size, other family income, child's age and rated health, and indicators of whether child is a boy, Hispanic, black–non-Hispanic, white–non-Hispanic, has limitations in activities of daily living/instrumental activities of daily living, lives in an MSA, lives in the Northeast, lives in the Midwest, lives in the West, and year.

<sup>b</sup> Tobit model is used in estimating dependent variables mother's hours of work, father's hours of work, and sum of mother's and father's hours of work per week. Coefficients represent marginal effects. All regressions include covariates listed above.

<sup>c</sup> Tobit model is used to estimate dependent variables mother's earnings, father's earnings, and sum of mother's and father's earnings per year. Coefficients represent marginal effects. All regressions include covariates listed above.

<sup>d</sup> Estimated coefficients are found to be significantly different at *p* = .05.

### Parental Weekly Hours of Work

In our sample, mothers of children with ASD worked, on average, 23 hours per week. There were no differences in maternal work hours among the 3 groups. Column 2 of Table 2 presents estimated tobit regression coefficients, which represent adjusted mean differences in parental weekly hours of work of children with another health limitation and children with no health limitation, compared with children with ASD. In adjusted analysis, mothers of children with no health limitation work an average of 7 hours more per week than the mothers of children with ASD.

Fathers of children with ASD worked 42 hours in a week, on average. Both unadjusted and adjusted analysis suggested no significant differences in fathers' hours of work among the 3 groups.

Total hours of work for families of children with ASD were 52 hours per week, on average, and were higher than those for families of children with another health limitation. In adjusted analysis, families of children with no health limitation work an average of 5 hours more per week than families of children with ASD.

### Parental Earnings

Mothers of children with ASD earned \$20 479 annually on average. Earnings of mothers of children with no health

limitation were \$5921 more than those of children with ASD. Column 3 of Table 2 presents estimated tobit regression coefficients, which represent adjusted mean differences in parental annual earnings of children with another health limitation and children with no health limitation, compared with children with ASD. In adjusted analysis, this difference increased to \$14 755 more for mothers of children with no health limitation compared with mothers of children with ASD.

In unadjusted analysis, there was no difference in maternal earnings between children with ASD and children with another health limitation. In adjusted analysis, mothers of children with another health limitation earn \$7189 more than mothers of children with ASD.

On average, fathers of children with ASD earned \$46 382 annually. In both unadjusted and adjusted analysis, there are no statistically significant differences in paternal earnings among the 3 groups.

Total earnings for families of children with ASD were \$57 100 annually on average. In unadjusted analysis, there were no statistically significant differences in family earnings among three groups. In adjusted analysis, families of children with another health limitation earned \$10 416 more and families of

children with no health limitation earned \$17 763 more per year than families of children with ASD.

In summary, mothers of children with ASD earn an average of 35% (\$7189) less than the mothers of children with another health limitation and 56% (\$14 755) less than the mothers of children with no health limitation. They are 6% less likely to be employed and work an average of 7 hours less per week than mothers of children with no health limitation. There are no differences in fathers' labor market outcomes across the 3 groups. On average, children with ASD are 9% less likely to have both parents working than children with no health limitation. Family earnings of children with ASD are 21% (\$10 416) less than those of children with another health limitation and 28% (\$17 763) less than those of children with no health limitation. Family weekly hours of work are an average of 5 hours less than those of children with no health limitation.

### DISCUSSION

This study shifts perspective in research on the costs of childhood ASD away from system-level health care costs toward family costs. This is the first study to examine, using a nationally representative data set, a wide range of parental labor market outcomes

associated with childhood ASD and to quantify an associated dollar cost. It is essential to account for such indirect costs in ongoing policy discussions regarding the best ways to support families and finance care for children with ASD.

Parents of children with emotional and behavioral disorders lack appropriate community-based services and resources needed to support work and family obligations.<sup>18</sup> Parents face difficulties balancing children's care needs and the demands of work. Finding accessible, affordable, and quality child care is difficult for many families of children with disabilities.<sup>19</sup> Therefore, many parents endure forced unemployment or reduce their work hours to care for their children, reducing their annual income.<sup>19</sup>

These effects are more pronounced for among families of children with autism. It is likely that because the systems that care for children with autism are so fragmented, many more challenges are raised for families in attending to the ongoing needs of their children. Parents are called on to serve as their child's caregiver, case manager, and advocate and to navigate numerous bureaucracies to obtain essential services for their child.<sup>20,21</sup>

This study compared parental labor market outcomes of children with ASD with those of children with another limitation and children with no health limitation. We found that it is the mother whose labor market outcomes are substantially affected by having a child with autism. This is not surprising; the mother is generally the primary caregiver and decision maker as to where and when health care services will be obtained and usually also accompanies the child to care. Mothers of children with ASD are less likely to work, work fewer hours per week, and earn substantially less than mothers of children with no health limitation. We did not find

significant differences in employment probability and hours of work between mothers of children with ASD and mothers of children with another health limitation. Maternal earnings of children with ASD, however, are significantly less than those of children with another health limitation. In our sample, mothers of children with ASD were significantly more educated and older (a proxy for more work experience) than the other 2 groups. Given the positive coefficients for education and age in our earnings regressions (not reported), our findings suggest that mothers of children with ASD, who potentially could earn more because of their higher educational level and age advantage, actually earn less as a result of the burden of caring for their children with ASD. Higher opportunity costs for these mothers are most likely to be underlying substantial differences in maternal earnings between mothers of children with ASD and mothers of the other 2 groups.

Our findings are consistent with previous studies that found that families of children with ASD were more likely to report that a family member reduced or stopped employment because of their child's condition,<sup>14,15</sup> and that mothers of children with ASD were less likely to be employed than other mothers.<sup>22</sup>

The major conclusion emerging from our analysis is that childhood autism has substantial economic impact on families. Given that these families face substantial health care expenses, the potential economic impact of having lower income in addition to these expenditures is substantial. Previous research suggests that, among families of children with ASD, likelihood of reporting financial problems was positively associated with having lower income.<sup>12</sup> Compared with children with other special health care needs, children with ASD were more likely to live in families that report financial problems,

need additional income for the child's medical care, or have reduced or stopped work because of the child's condition.<sup>14</sup>

Some limitations should be considered when interpreting these results. First, our analyses are based on cross-sectional data; they do not permit firm conclusions about causal relationships among variables. It could be that independent variables for children with ASD may differ from other children for reasons unrelated to the child's condition that we cannot observe within the available data. We attempted to address this limitation by including a rich set of measures of child, household, and parental characteristics. Second, we were limited in our ability to account for local labor market conditions, which are likely to affect parental labor supply. We attempted to address this limitation by using region and metropolitan statistical area status of residence and year as controls for labor market conditions. A related concern is that we collapsed 7 years of data. Diagnostic practices and service availability for children with autism likely have changed over that period of time. The small sample of children with ASD within each year of data precludes examining only the most recent data or providing temporal trends.

Despite these limitations, our findings have important implications. The elevated cost of raising children with ASD means those families must have a stable, adequate income to provide the specialized care their children's needs. Therefore, parental employment might be vitally important for these families' financial well-being. This suggests the need for additional evaluation of available supports for families and specific barriers to optimizing family income. It is essential to design both universal health care and workplace policies that recognize the full impact of autism, as well as targeted policies

and resources to alleviate costs for the families with greatest needs.

When evaluating new interventions and policies, it is important to include costs and benefits to all parties affected by an

intervention, including the family.<sup>23,24</sup> Accurately accounting for family effects in cost-effectiveness analyses can improve our understanding of the full costs and benefits of ASD-related

interventions and guide policy makers in allocating resources for ASD treatment. Otherwise, undervaluing new financing policies are likely to create negative consequences for families.

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