

# Economic Burden of Childhood Autism Spectrum Disorders



**WHAT'S KNOWN ON THIS SUBJECT:** Previous analyses have documented increased health care costs for children with autism spectrum disorders but have not provided comprehensive estimates of the total economic burden.



**WHAT THIS STUDY ADDS:** There are substantial additional costs associated with caring for children with autism spectrum disorders, amounting to >\$17 000 per child annually. Costs accrued outside of the health care system account for the majority of the financial burden.

## abstract



**OBJECTIVE:** To estimate the associations between autism spectrum disorder (ASD) diagnoses and service use, caregiver time, and cost outcomes.

**METHODS:** We used national data from the Medical Expenditure Panel Survey linked to the National Health Interview Survey and a study-specific survey to estimate the annual utilization and costs for health care, school, ASD-related therapy, family-coordinated services, as well as caregiver time in children aged 3 to 17 years, with and without parent-reported ASD. Regression analyses estimated the association between ASD diagnosis and cost, controlling for child gender, age, race/ethnicity, insurance status, household income, country region and urban/rural classification, and non-ASD-related illnesses.

**RESULTS:** Children with parent-reported ASD had higher levels of health care office visits and prescription drug use compared with children without ASD ( $P < .05$ ). A greater proportion of children in the ASD group used special educational services (76% vs 7% in the control group,  $P < .05$ ). After adjusting for child demographic characteristics and non-ASD-associated illnesses, ASD was associated with \$3020 (95% confidence interval [CI]: \$1017–\$4259) higher health care costs and \$14 061 (95% CI: \$4390–\$24 302) higher aggregate non-health care costs, including \$8610 (95% CI: \$6595–\$10 421) higher school costs. In adjusted analyses, parents who reported that their child had ASD did not have significantly higher out-of-pocket costs or spend more time on caregiving activities compared with control parents.

**CONCLUSIONS:** The economic burden associated with ASD is substantial and can be measured across multiple sectors of our society. Previous analyses that focused on health care underestimated this economic burden, particularly for school systems. *Pediatrics* 2014;133:e520–e529

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### KEY WORDS

cost of illness, health economics, autism spectrum disorder

### ABBREVIATIONS

ASD—autism spectrum disorder

CI—confidence interval

GLM—generalized linear model

MEPS—Medical Expenditure Panel Survey

NHIS—National Health Interview Survey

PDD-NOS—pervasive developmental disorder, not otherwise specified

Dr Lavelle contributed to the conceptualization and design of the study, coordinated data collection, carried out all data analyses, drafted the manuscript, had full access to all of the data in the study, and takes responsibility for the integrity of the data and the accuracy of the data analysis; Drs Weinstein, Newhouse, Munir, and Prosser contributed to the conceptualization and design of the study and reviewed and revised the manuscript; Dr Kuhlthau contributed to the conceptualization and design of the study and critically reviewed the manuscript; and all authors approved the final manuscript as submitted.

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Over the past decade, the prevalence of autism spectrum disorder (ASD) diagnoses has increased considerably. The most recent data released from the Autism and Developmental Disabilities Network reveal a 78% increase in ASD prevalence between 2002 and 2008,<sup>1</sup> and data from the National Survey of Children's Health reveal that the prevalence of parent-reported ASD among children aged 6 to 17 years increased from 1.2% in 2007 to 2.0% in 2011–2012.<sup>2</sup> The increasing prevalence highlights a growing need for resources to provide care for this population of children. Studies have shown that families of children with ASD face high out-of-pocket costs.<sup>3–9</sup> To date, however, there has not been a comprehensive pediatric cost analysis of ASD in the United States. Previous analyses have mainly focused on health care,<sup>8–13</sup> despite evidence that costs incurred outside of the health care system may play a more important role in the total economic burden of ASD.<sup>3,14</sup>

In this study, we used data from 3 national sources to estimate the total economic costs associated with pediatric ASD and the out-of-pocket costs specifically borne by families. We compared the following sources of cost for children with and without parent-reported ASD: the annual utilization of health care, school, ASD-related therapy, family-coordinated services, and caregiver time.

## METHODS

### Study Samples

Study samples included children between the ages of 3 and 17 years with and without parent-reported ASD. To estimate annual health care utilization and costs, we linked observations from the cross-sectional Medical Expenditure Panel Survey (MEPS) to the Sample Child Core questionnaire in the National Health Interview Survey (NHIS).<sup>15,16</sup> The NHIS is administered each year to

a new sample of US households with noninstitutionalized adults and children. General health data are collected from all members of the sampled households, and more detailed health information is collected on 1 child in the household for the Sample Child Core questionnaire. In this study, children with a positive response to the NHIS Sample Child Core question “Has a doctor or health care provider ever told you that [child's name] has autism?” were assigned to the ASD group. The control group was composed of children with a negative response. The MEPS collects more detailed health care utilization and expenditure data from a representative subset of households from the previous year's NHIS sample, and follows this sample subset over a 2-year period.

We used individual ID numbers to link 23 057 observations of children who had records in both the NHIS Sample Child Core from 2001 to 2007 and the MEPS from 2003 to 2008. These linkable observations were 19% of the total NHIS Child Core sample and 13% of the MEPS sample. Twelve children were eliminated from the linked sample for not having an indicator of ASD illness, and an additional 4161 children were eliminated for being outside of the 3- to 17-year age range when their MEPS data were collected, which left a final sample size of 18 884 (109 children with parent-reported ASD and 18 775 controls; Fig 1).

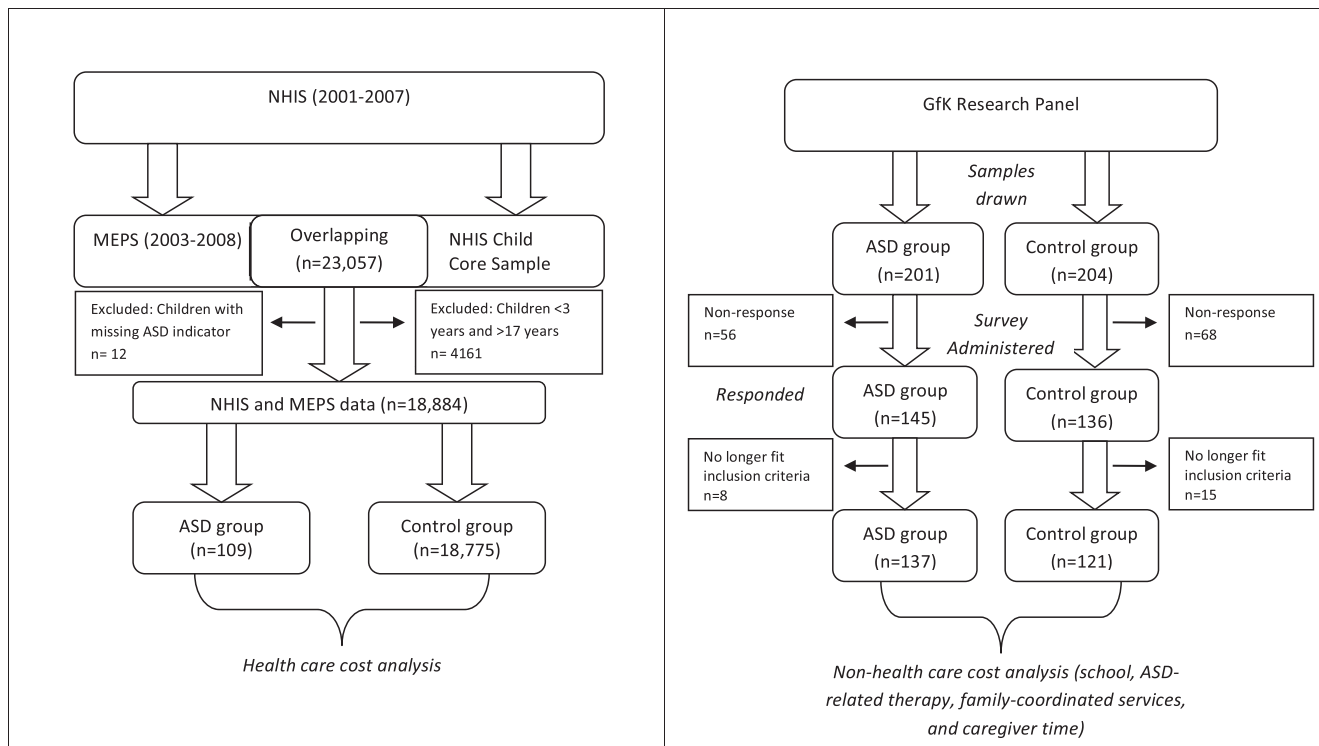
To estimate non-health care utilization and expenditures, a survey was administered to 2 groups of parents enrolled in a survey research panel managed by GfK Custom Research, LLC. This research panel is nationally representative; new panel members are currently recruited by mail by using probability sampling from a published address-based sample frame that covers ~98% of US households.<sup>17</sup> Of all households initially contacted to join the survey panel along with our study sample, 16% had at least 1 household member who

was successfully recruited. Panel members are asked to complete online surveys 3 to 4 times per month. Those without previous Internet access are provided with a laptop computer and Internet service while on the panel; those with Internet access are given small monthly stipends in exchange for their participation.<sup>18</sup> All panel members are asked to complete a series of profile questions to determine their eligibility for specific surveys.

A total of 201 potential respondents for our ASD group were randomly sampled from all survey panel members who had previously indicated on their GfK profile survey that they were the caregiver of a child under 18 years with autism or Asperger's, and 204 potential respondents for our control group of parents of children without ASD were randomly selected from all parents on the panel who had a negative response to this profile question.

A link to a screener questionnaire was e-mailed to the 405 survey panel members during October 2011. Screener questions asked parents whether they had a child between the ages of 3 and 17 years, and whether any of their children in this age range had been diagnosed with ASD, including autism, Asperger's syndrome, or pervasive developmental disorder, not otherwise specified (PDD-NOS). Those in the ASD group who responded positively to both questions were then asked to complete a 25-minute online survey; those in the control group were asked to continue onto the survey if they had a child in this age range and no children in the range with ASD.

We received responses from 72% ( $n = 145$ ) of parents in the ASD group and 67% ( $n = 136$ ) of controls after 2 e-mail reminders. Compared with nonrespondents, respondents were more likely to have previous Internet access ( $P < .01$ ) and a bachelor's degree or higher ( $P = .04$ ), but other demographic characteristics were not statistically different.



**FIGURE 1**  
Study inclusion flowcharts for health care and non-health care analyses.

Twenty-three respondents were excluded from the sample at the screening stage on the basis of age and diagnosis criteria, 8 from the ASD group and 15 from the control group, leaving a final sample size of 258 (137 ASD, 121 controls; Fig 1). This study was approved by the Harvard University Institutional Review Board. All data were deidentified, and no informed consent was required.

### Outcomes and Study Variables

Our primary outcomes of interest were annual utilization and costs for health care, school services, ASD-related therapies, family-coordinated services, and caregiver time (full classification of each category available in Supplemental Table 5). We estimated total costs for each category and family out-of-pocket costs for all services.

We measured health care utilization for all categories reported in the MEPS data set including hospitalizations, office and emergency department visits, home health care, dental care visits, and

prescription drug use. Total costs were assessed by using payments from all sources, including household and insurance payments; out-of-pocket costs were derived from household payments only.

School resource utilization was examined broadly by type of school (public, private day, residential, home, or other), classroom type (special, general education), and whether the child qualified for and used special education services through an Individualized Education Program. Children were categorized into 11 mutually exclusive school placements on the basis of their school type, special education use, and age. Previously published unit cost estimates for total annual education expenditures by school placement type were applied to these classifications to estimate the annual education costs at all public and residential schools, as well as private schools providing special education services (Supplemental Table 6).<sup>19–22</sup> Reported tuition expenditures from all

sources were used to assess the total cost of educating children in private day schools without any special education services. Out-of-pocket costs for all school placements were based on the reported family tuition expenditures.

We used the parent survey to measure utilization and expenditures for ASD-related therapies that were not included in the MEPS data. These include treatments such as applied behavioral analysis, sensory integration, and communication therapies. All other resources used to care for children with parent-reported ASD are categorized as “family-coordinated services” for the purposes of this analysis. This is a broad category that includes items such as child care, legal services, and transportation. Costs for ASD-related therapies and family-coordinated services were based on reported expenditures by the family or other source excluding their school system (ie, insurance, Department of Developmental Services, charity, foundation, scholarship, fellowship).

Out-of-pocket costs reflect family expenditures only.

Caregiving time was measured as the amount of time all caregivers in the household had reportedly spent on activities such as coordinating their child's therapies, homework help, and travel to appointments and activities during the previous 12 months. Time costs were converted to a dollar value by multiplying the number of hours spent on each caregiving activity by the 2011 mean wage rate for all US workers (\$23/hour).<sup>23</sup>

Our study survey and MEPS provided data on child demographic characteristics, health insurance coverage, geographic region, household income, and health conditions. In our survey we asked parents of children with ASD to report their child's specific diagnosis (autism, Asperger's syndrome, or PDD-NOS) and the severity of the child's social communication problems and restricted interests/repetitive behavior domains. A 3-level composite severity score (mild, moderate, severe) was derived on the basis of the reported severity levels on these 2 domains (Supplemental Fig 3).

## Analyses

We compared demographic and clinical characteristics for the ASD and control groups by using  $\chi^2$  tests. We compared service utilization and caregiving hours for the ASD and control groups by using  $\chi^2$  tests for categorical measures and nonparametric Kolmogorov-Smirnov tests for continuous measures.<sup>24</sup> To estimate the association between ASD diagnosis and cost outcomes, we used generalized linear models (GLMs) with a log link function.<sup>25</sup> The GLM was used in combination with a logit model to create a 2-part model for cost categories with  $\geq 50\%$  zero-cost observations. For analyses of health care costs we used the generalized estimating equation extension of the GLM to account for

the multiple observations per subject in the sample, and also evaluated a 2-part model in a sensitivity analysis.

In adjusted analyses we controlled for variables that had previously been identified as having an impact on costs, independent of health status.<sup>9,26–29</sup> These included child gender, age, race/ethnicity, insurance status, household income, geographic region, and urban/rural classification. We also controlled for the presence of other illnesses that do not have an established association with ASD<sup>30,31</sup> and that were available in all data. These included allergies, arthritis, asthma, cerebral palsy, cystic fibrosis, diabetes, diarrhea/colitis, Down syndrome, hearing impairment, heart disease, muscular dystrophy, sickle cell anemia, and vision impairment. In sensitivity analyses we added an indicator variable for the presence of epilepsy or intellectual disability to our model, to evaluate the influence of controlling for these conditions with established associations with ASD.<sup>32,33</sup>

Confidence intervals (CIs) around all mean values and regression coefficients were estimated using nonparametric bootstrapping procedures.<sup>34</sup> The goodness of fit of each GLM was measured by using a test of concordance between the observed and predicted costs.<sup>35</sup> All cost data were updated to 2011 US dollars by using the Gross Domestic Product deflator.<sup>36</sup> To reduce the influence of outliers, costs derived from MEPS and the study survey were truncated at the 99th and 90th percentiles, respectively.

## RESULTS

### Study Samples

In both study samples, children with parent-reported ASD were significantly more likely than controls to be male, over the age of 5 years, and non-Hispanic white. Children with parent-reported ASD were also significantly more likely to have certain comorbid conditions,

including allergies, attention-deficit/hyperactivity disorder, and intellectual disability ( $P < .05$  for all; Table 1).

### Resource Utilization

Ninety-two percent of children in the ASD group had used some form of health care during the year compared with 82% in the control group ( $P = .01$ ). On average, children with parent-reported ASD had significantly higher levels of physician and nonphysician office visits and prescription drug use compared with children in the control group ( $P < .05$  for all). Other health care service use did not differ significantly between the 2 groups (Table 2).

School placements differed significantly between the ASD and control groups. A greater proportion of children in the ASD group attended public school or were home schooled (85%) during the year compared with the control group (65%). Seventy-six percent of the children in the ASD group used special education services through an Individualized Education Program compared with 8% in the control group ( $P < .05$  for all; Table 3). The use of special education services ranged from 73% for children with mild ASD to 91% for children with severe ASD, and was least likely among children with a specific diagnosis of Asperger's syndrome, although differences between subgroups were not statistically significant (Supplemental Tables 7 and 8).

Thirty-one percent of children with parent-reported ASD used some form of ASD-related therapy during the year, such as applied behavior analysis or sensory integration therapy. Compared with children in the control group, a significantly greater proportion of children in the ASD group used legal aid, private academic tutors, or private school observation services ( $P < .05$  for all; results not shown). Total caregiving hours did not differ significantly between the groups.

**TABLE 1** Child Demographic and Clinical Characteristics

Characteristic	MEPS			Study Survey		
	ASD ( <i>n</i> = 109), %	Control ( <i>n</i> = 18 775), %	<i>P</i>	ASD ( <i>n</i> = 137), %	Control ( <i>n</i> = 121), %	<i>P</i>
Male	83.7	51.2	<.01	80.3	65.3	.01
Age			<.01			.01
3–5 years	9.2	22.7		8.0	21.7	
6–10 years	49.5	31.2		32.9	34.2	
11–13 years	21.1	18.8		24.1	18.3	
14–17 years	20.2	27.3		35.0	25.8	
Insurance			.01			.35
Any private	59.6	51.4		71.3	66.7	
Public only	37.6	40.7		25.7	26.7	
None	2.8	7.9		2.9	6.7	
Race/ethnicity			.02			<.01
White, non-Hispanic	60.6	41.2		82.5	68.6	
Black, non-Hispanic	11.0	18.6		4.4	10.7	
Hispanic	21.1	32.8		7.3	2.5	
Non-Hispanic, other	7.3	7.4		5.8	18.2	
Region			.88			.87
Northeast	18.4	14.9		20.4	21.5	
Midwest	18.4	19.0		23.4	19.0	
South	34.9	38.6		31.4	33.9	
West	28.4	27.5		24.8	25.6	
MSA						
Urban	91.7	83.1	.01	84.7	85.1	.92
Income (% of FPL)			.03			.85
≤100%	13.8	25.0		11.0	12.4	
100% to 199%	25.7	26.3		24.1	19.8	
200% to 299%	39.5	27.6		20.4	19.8	
≥300%	21.1	21.1		44.5	48.0	
Comorbid health conditions						
Allergies <sup>a</sup>	44.0	25.1	<.01	51.1	18.2	<.01
Anxiety	NA <sup>b</sup>	NA	NA	34.3	5.0	<.01
Asthma	19.3	13.6	.27	10.2	9.9	.94
Attention-deficit/hyperactivity disorder	44.0	6.1	<.01	43.8	8.3	<.01
Bipolar	NA	NA	NA	3.7	1.7	.32
Cerebral palsy	1.8	1.8	.97	3.7	0.0	.03
Depression	NA	NA	NA	6.6	2.5	.12
Epilepsy	0.0	0.2	.63	7.3	0.0	<.01
Gastrointestinal	8.3	1.7	.06	8.8	0.8	<.01
Hearing problem	4.6	3.0	.49	2.9	0.8	.22
Heart disease <sup>c</sup>	5.5	1.5	.16	1.5	0.0	.18
Intellectual disability	15.6	0.5	<.01	18.3	0.0	<.01
Obsessive-compulsive disorder	NA	NA	NA	18.3	2.5	<.01
Sleep disorder	NA	NA	NA	10.2	2.5	.01
Vision problem	0.9	2.4	.1	5.8	0.8	.03

*P* values were calculated by using  $\chi^2$  tests. All comparisons are based on unweighted data. FPL, Federal Poverty Level; MSA, Metropolitan Statistical Area; NA, not available.

<sup>a</sup> Includes hay fever, respiratory allergy, food/digestive allergy, and eczema/skin allergy.

<sup>b</sup> Not available in the MEPS data set.

<sup>c</sup> Congenital or other.

## Costs

Having ASD was significantly associated with \$3020 (95% CI: \$1017–\$4259) higher health care costs after adjusting for demographic and non-ASD-associated illnesses in our primary analysis. Regression-adjusted school costs were \$8610 (95% CI: \$6595–\$10 421) higher for children with ASD. Costs associated with ASD-related therapies and other

family-coordinated services were not significantly higher in the ASD group, nor were caregiving time costs. When the 3 non-health care categories were examined in aggregate, however, their total cost was \$14 061 (95% CI: \$4390–\$24 302) higher in the ASD group. Out-of-pocket costs were not significantly higher for the ASD group in any category (Table 4; full models for health care

and aggregate non-health care costs are shown in Supplemental Tables 9 and 10). Concordance coefficients for all models ranged from 0.08 to 0.73 and were all significantly greater than zero, indicating a significant and positive correlation between observed and predicted costs.

In sensitivity analyses, the association between ASD and health care costs

**TABLE 2** Health Care Utilization

Health Care Resource Category	ASD			Control			P
	Mean	95% CI	Median	Mean	95% CI	Median	
Nights in inpatient hospital	0.3	0.0–0.7	0.0	0.1	0.1–0.1	0.0	.1
Outpatient visits (total)	10.7	5.8–16.3	4.0	3.7	3.7–3.9	2.0	.04
Outpatient hospital <sup>a</sup>	0.3	0.0–0.6	0.0	0.1	0.1–0.2	0.0	.38
Physician office	5.2	2.8–7.6	2.0	1.8	1.7–1.9	1.0	.02
Nonphysician office <sup>b</sup>	3.1	1.9–5.5	0.0	0.7	0.7–0.8	0.0	<.01
Emergency department	0.1	0.1–0.2	0.0	0.2	0.2–0.2	0.0	.13
Home health care visits <sup>c</sup>	11.6	0.3–19.9	0.0	0.3	0.2–0.4	0.0	.12
Dental care visits	1.2	0.9–1.7	1.0	1.1	1.1–1.2	0.0	.82
Prescription medications with refills	11.4	7.4–16.3	3.0	2.6	2.5–2.7	0.0	<.01

95% CIs are bootstrapped by using a clustered variance to account for multiple observations per person.

<sup>a</sup> Physician and nonphysician visits.

<sup>b</sup> Includes chiropractors, midwives, nurses and nurse practitioners, optometrists, podiatrists, physician assistants, physical therapists, occupational therapists, psychologists, social workers, technicians, and receptionists/clerks/secretaries.

<sup>c</sup> Includes agency and nonagency home health care.

decreased to \$2373 (95% CI: \$902–\$3695) when modeled by using a 2-part model. The association between ASD and out-of-pocket health care costs became significant in a 2-part model, with the ASD group having \$154 (95% CI: \$3–\$344) higher costs compared with

controls. Health care costs were no longer significantly higher in the ASD group when we controlled for the presence of epilepsy or intellectual disability. The association between ASD and aggregate non-health care costs decreased to \$10508 (95% CI: \$725–\$20586) when we controlled for these comorbidities.

In subgroup analyses, regression-adjusted aggregate non-health care costs were significantly higher for mild, moderate, and severe ASD, compared with no ASD, and increased with each severity level (Supplemental Table 11). A specific diagnosis of autism was associated with higher aggregate non-health care costs, but specific diagnoses of Asperger's syndrome and PDD-NOS were not (Supplemental Table 12). Each severity level and subtype of ASD significantly predicted higher school costs. The most severe level of ASD was significantly associated with \$21313 (95% CI: \$6556–\$39473) higher caregiver time costs compared with a child without ASD (Fig 2). Similar to the overall group, this significant association did not persist among children with less severe levels of ASD, or among any of the 3 specific subtypes of ASD.

## DISCUSSION

This is the first study to our knowledge to provide comprehensive estimates of

the total economic burden of childhood ASD. Using 3 national data sets, we found that the additional costs of caring for a child with parent-reported ASD, including health care, education, ASD-related therapy, family-coordinated services, and caregiver time, totaled \$17081 per year. Applying these estimates to the projected 673000 children aged 3 to 17 years in the United States with ASD,<sup>37</sup> the total societal costs of caring for this group of children were \$11.5 billion in 2011.

Despite the literature's emphasis on estimating health care costs for this population of children, we find that these costs are not the main contributor to the overall economic burden of this disorder. Of the estimated \$17000 additional costs we found to be associated with childhood ASD annually, only 18% were attributable to the increased use of health care services, specifically office visits and prescriptions. Our estimated health care costs are within the range of previously derived estimates, which show additional costs for children with ASD ranging from \$2191 to \$11590 per year (2011 US dollars).<sup>8–13</sup> Differences in data sources, comparison groups, and analytic methods contribute to the substantial variation in these results.

School services were the biggest contributor to costs associated with childhood ASD due to the increased use of special education services in this group. Although previous studies have estimated costs for children with ASD in special education,<sup>19</sup> this is the first study to estimate educational costs for all children with parent-reported ASD. The results highlight the economic burden placed on this sector and the need for policies to ensure that resources are available to school systems to provide needed services in the future. Under federal law, students with disabilities are entitled to special education and related services through age

**TABLE 3** School Resource Utilization

	ASD, %	Control, %	P
School type			<.01
Public, nonresidential	78.1	62.1	
Private, nonresidential	8.8	18.1	
Residential school	3.7	8.6	
Home school	6.6	2.6	
No school	0.7	6.9	
Other	2.2	1.7	
Classroom type <sup>a</sup>			<.01
General education only	50.8	93.5	
General and special education	37.1	4.4	
Special education only	12.1	1.1	
Other	0.0	1.1	
Educational accommodations			<.01
Individualized Education Program <sup>b</sup>	75.7	7.5	
504 Plan <sup>c</sup>	4.4	4.7	
None	19.9	87.9	

<sup>a</sup> Among those children enrolled in public, private, residential or other schools. Does not include children who are home schooled.

<sup>b</sup> Indicates eligibility for, and use of, special education services in public schools. It contains information regarding the child's present level of functioning, goals, and services to be provided.

<sup>c</sup> A 504 Plan is a document for children in public schools with physical or mental health disabilities who are not eligible for special education services. It lists special accommodations required by the child so that he or she may participate in the general classroom setting and educational programs.

**TABLE 4** Summary of the Regression-Adjusted Difference in Costs for Children With ASD Compared With Children Without ASD

Category	Total costs, <sup>a</sup> \$	95% CI	Out of pocket costs <sup>a</sup> , \$	95% CI
Health care	3020	1017 to 4259	182	-6 to 299
Total aggregate non-health care	14 061	4390 to 24 302	-112	-715 to 749
School	8610	6595 to 10 421	-462	-3496 to 189
ASD-related therapy and other family-coordinated services	350	-76 to 972	81	-318 to 523
Time	5089	-1672 to 11 936	—	—

<sup>a</sup> Adjusted for child gender, age, race/ethnicity, insurance status, household income, geographic region, urban/rural classification, and the presence of a comorbidity not related to ASD.

21. Previous research has suggested that after this time the cost burden may shift to sectors that provide adult-based services.<sup>3</sup>

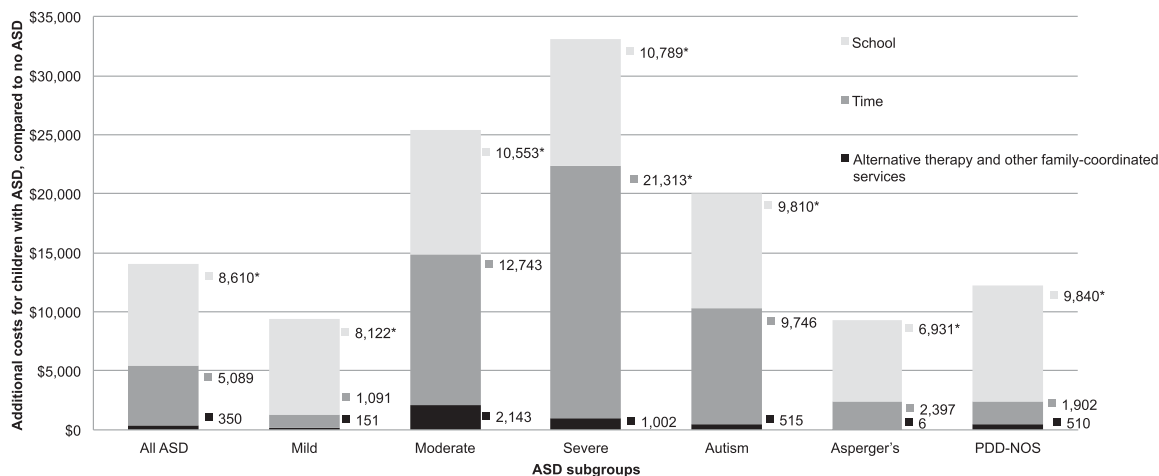
Previous studies on this topic are limited, particularly in the United States. A study of children with ASD in a Swedish municipality reported the additional annual cost associated with this disorder to be ~€50 000 per child (\$68 000 in 2011 US dollars),<sup>38</sup> and a study of children with ASD in the United Kingdom reported an additional annual per capita cost of ~£25 000 (\$44 063 in 2011 US dollars).<sup>39,40</sup> In the United States, Ganz<sup>3</sup> estimated the additional lifetime costs associated with ASD to be \$3.2 million per person (\$3.8 million in 2011), including the costs for health care, special education, child and adult care, respite services, supported employment, and lost productivity. Although

these estimates indicate a greater economic burden than one would infer from our study, direct comparisons between studies are not possible due to different country settings and different time horizons of the analyses.

Previous studies have also found that parents of children with ASD endure substantial financial burdens, in the form of high out-of-pocket costs, and decreased work force involvement.<sup>3-9</sup> In our study we did not find that parents of children with ASD in the overall group had higher out-of-pocket costs or spent more time on caregiving activities compared with parents of children without ASD. We did find that parents in the ASD group reported more time than those in the control group on several specific caregiving activities, such as coordinating their child's medical care and therapy and providing homework

help, and reported less time on "general daily household caregiver activities." This shift from general to specific caregiving activities for parents of children with ASD is important to note, because it could have important implications for the care of other children in the household. More studies are needed to provide a better understanding of the financial impact of ASD on families and how it may be evolving over time, particularly as states continue to enact legislative mandates requiring private insurance companies to cover additional ASD-related services.<sup>41</sup> One study found that families of children with ASD living in states with ASD-specific parity laws were less likely to have health-related out-of-pocket expenditures compared with families living in states without mandates.<sup>42</sup>

We did find that having a child with the most severe level of ASD was associated with higher caregiving time costs. We accommodated social communication problems and restricted interest/repetitive behaviors domains in our composite assessment of severity, which is unique for this study. It is important to note that there is currently no universal tool used to assess the severity of children with ASD.<sup>43</sup> In light of the recent



**FIGURE 2** Regression-adjusted differences in non-health care costs for children with ASD compared with children without ASD, by severity and diagnostic subgroups. \*Statistically significant difference compared to children without ASD ( $P < .05$ ).

revision of the *Diagnostic and Statistical Manual of Mental Disorders (Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition)*, which collapses subtypes of ASD into 1 diagnosis,<sup>44</sup> these results emphasize the importance of a consistent measure of severity that can provide important categorizations of this broad disorder. Diagnoses of ASD under the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*, include level of severity assessments for social communication and restricted, repetitive behaviors. Such classifications could help to quickly identify families who may face increased caregiving demands.

Some limitations of the study must be noted. Due to the observational nature of our study we are not able to draw causative conclusions. Relatively small sample sizes may have limited our ability to detect important cost differences. Although our study benefited from national samples, these samples were different for our health care and non-health care analyses, and were not necessarily representative of the broader populations of families of children with and without ASD. In particular, low recruitment rates for the panel used for our survey of non-health care utilization may have contributed to selection bias. Controlling for observed demographic variables in adjusted cost analyses allowed us to mitigate the impact of potential selection biases, but the impact of unmeasured confounding variables on our estimates is not known. We also controlled for comorbidities in our regression analyses that do not have an established association with ASD,<sup>30,31</sup> but if a causal association does exist between any of these conditions and ASD, then our adjusted results will underestimate the total costs attributable to ASD.

Linking MEPS data to the NHIS allowed us to identify children with parent-reported ASD who did not have any health care use, but identification through the NHIS has some limitations. Specifically, parents are asked report whether their child has ever been diagnosed with autism, not ASD, and diagnoses of Asperger's syndrome and PDD-NOS may be underreported. In addition, diagnoses of ASD do not necessarily remain stable over time.<sup>1,37,45</sup> If there was any misclassification between our ASD and control groups at the time of resource utilization, then our findings may be biased toward the null.

All diagnoses were ascertained via parent report; previous research has revealed that parent report of ASD is highly reliable when verified against professional diagnostic documentation,<sup>46</sup> but limited data are available about the reliability of parent report of specific diagnoses within the spectrum and misclassification may have occurred. Parent report was also used to document caregiver time and non-health care service utilization and expenditures over the previous 12 months. This time interval was chosen to include both the school year and summer time, 2 periods during which the intensity of services and time commitments may be different, but the long recall period may have led to underreporting.<sup>47</sup>

The results of this study reveal the current economic costs associated with caring for children with ASD, but they do not address how current investments may lead to a change in the future trajectory of services required. This study also does not indicate whether these costs reflect an optimal level of resources, or whether resources are being used efficiently, which highlights the need for cost-effectiveness analyses

to provide guidance on how to improve the allocation of resources devoted to ASD.<sup>48</sup> And finally, this study addresses only the cost burden associated with ASD, and not the impact that ASD has on the health and well-being of family members; previous research has shown that children with ASD and their families have diminished health-related quality of life.<sup>49</sup>

## CONCLUSIONS

There is a large economic burden associated with caring for a child with ASD, a substantial portion of which is borne by the educational system, principally the cost of special education services in public schools. These costs have been underrecognized. Families of children with the most severe level of symptoms also face large caregiving demands and severity measures may help highlight those in greatest need for support. Comprehensive policies are needed to ensure that funds are allocated to meet the needs of this population, and future cost-effectiveness analyses should inform how these funds are spent to ensure the best possible outcomes for children with ASD.

## ACKNOWLEDGMENTS

The authors thank Ellen Lipstein, MD, MPH (Department of Pediatrics, University of Cincinnati College of Medicine and Cincinnati Children's Hospital Medical Center), Kelly Sandberg, MD (Department of Pediatrics, Child Health and Evaluation Research Unit, University of Michigan), and Davene Wright, PhD (Department of Pediatrics, University of Washington School of Medicine and Seattle Children's Research Institute) for their review and comments on a previous version of this manuscript. No compensation was provided for this review.



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[www.pediatrics.org/cgi/doi/10.1542/peds.2013-0763](http://www.pediatrics.org/cgi/doi/10.1542/peds.2013-0763)

doi:10.1542/peds.2013-0763

Accepted for publication Dec 5, 2013

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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

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**FINANCIAL DISCLOSURE:** The authors have indicated they have no financial relationships relevant to this article to disclose.

**FUNDING:** Funding for this study was provided by the National Institute of Mental Health (5T32MH019733-18), Harvard University's Center for American Political Studies, the National Institute of Mental Health Research Training Program in Mental Health and Developmental Disabilities at Boston Children's Hospital (R25 MH071286), National Institute for Nursing Research (7-R01-NR-011880-03), Harvard University Graduate School of Arts and Sciences, and the Nancy Lurie Marks Foundation.

**POTENTIAL CONFLICT OF INTEREST:** The authors have indicated they have no potential conflicts of interest to disclose.