

The Lifetime Distribution of the Incremental Societal Costs of Autism

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Objective: To describe the age-specific and lifetime incremental societal costs of autism in the United States.

Design: Estimates of use and costs of direct medical and nonmedical care were obtained from a literature review and database analysis. A human capital approach was used to estimate lost productivity. These costs were projected across the life span, and discounted incremental age-specific costs were computed.

Setting: United States.

Participants: Hypothetical incident autism cohort born in 2000 and diagnosed in 2003.

Main Outcome Measures: Discounted per capita incremental societal costs.

Results: The lifetime per capita incremental societal cost of autism is \$3.2 million. Lost productivity and

adult care are the largest components of costs. The distribution of costs over the life span varies by cost category.

Conclusions: Although autism is typically thought of as a disorder of childhood, its costs can be felt well into adulthood. The substantial costs resulting from adult care and lost productivity of both individuals with autism and their parents have important implications for those aging members of the baby boom generation approaching retirement, including large financial burdens affecting not only those families but also potentially society in general. These results may imply that physicians and other care professionals should consider recommending that parents of children with autism seek financial counseling to help plan for the transition into adulthood.

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AUTISM IS A VERY EXPENSIVE disorder costing our society upwards of \$35 billion in direct (both medical and nonmedical) and indirect costs to care for all individuals diagnosed each year over their lifetimes.¹ Given the financial and nonfinancial costs we face and given increasingly more options for treatment and possibly for prevention, information on the distribution of costs is needed to help us decide on how to best allocate scarce resources to support individuals with autism and their families. Because the complementary (or competing) treatment and prevention strategies currently available, or yet to be developed, vary in effectiveness or implementation costs, understanding how total costs due to autism are distributed across the life cycle is important to make better decisions.

Relatively little is known about the societal costs of autism, in total and at different points across the life cycle. In earlier work, the per capita and total societal costs for individuals with autism were described.¹ Although the per capita and societal costs were described overall and across 17 components of direct medical, direct nonmedical, and indirect costs, age-specific costs were not. Because certain cat-

egories are more relevant and more costly and because these costs are borne by different parties at different ages, presenting the age distribution of the costs of autism can provide policy makers information that is helpful for cost-utility analyses and for current and future resource planning activities. The focus of this study is to present estimates of the costs of autism along with some detail on how the estimates were constructed. Although no clinical data are presented, these data should be useful to health care professionals, families, and agencies in planning for future care, especially with respect to nonmedical costs.

METHODS

A detailed description of the sources of data and computational methods used to compile the costs of autism has been presented elsewhere.¹ Briefly, cross-sectional cost data from different age groups were used to create prevalence-based cost estimates that approximate incidence-based estimates (ie, those constructed by longitudinally tracking an incident cohort over time). A prevalence-based cohort, also known as a synthetic, or hypothetical, cohort,² allows us to approximate the lifetime experiences of a single incident cohort by using the prevalence-based cost patterns as if

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they were observed longitudinally from an incident cohort. Although an incidence-based cost-of-illness approach is more appropriate because it captures the full experience of autism, including any comorbid conditions, formidable data requirements preclude it.³

The total costs of autism equal the sum of its direct and indirect costs. Direct costs measure the value of goods and services used and indirect costs measure the value of lost productivity due to autism. These direct and indirect costs represent the value of other activities that these resources could have purchased (ie, opportunity costs).^{4,5} Physician and other professional services, hospital and emergency department services, drugs, equipment and other supplies, and medically related travel and time costs are typical components of direct medical costs. Direct medical costs were obtained either from the literature or from an analysis of the Medical Expenditure Panel Survey (MEPS)⁶ and the National Health Interview Survey (NHIS).⁷ Special education, transportation, child care and babysitting, respite care, out-of-home placement, home and vehicle modifications, and supported employment services are typical components of direct nonmedical costs. Nonmedical costs were obtained from the literature. Multiple cost estimates within categories were averaged to obtain a single cost estimate for each category. Indirect costs are the value of lost or impaired work time (income), benefits, and household services of individuals with autism and their caregivers because of missed time at work, reduced work hours, switching to a lower-paying but more flexible job, or leaving the workforce. Indirect costs were computed using a human capital approach^{3,8} that combines average earnings, benefits, and household services with information on average work-life expectancies and labor force participation rates for men and women at different ages.

In the analyses that follow, the incremental costs of autism are presented, which are defined as those additional costs that are due exclusively to autism. For example, costs due to use of medical services for periodic well-child preventive care or care related to the common cold are not considered herein because those costs are common to children with and without autism; however, costs specifically due to autism are considered herein. When incremental costs were not available or otherwise specifically presented in the source materials, they were computed by subtracting national average costs calculated from the MEPS from the costs reported in the source documents. For example, if a source document presented an average cost of \$X for all children with autism and the national average for all children for that same category was \$Y, then the incremental cost was computed as \$(Y-X). Because of the broad impact of autism on families, insurers, taxpayers, and society and because of the considerable public autism funding, a societal perspective was used, as recommended by the Panel on Cost-effectiveness in Health and Medicine.⁸

The Harvard School of Public Health Human Subjects Committee had previously exempted this study from institutional approval.

DIRECT COSTS

Literature Review

An in-depth targeted literature review concentrating on US-based studies was conducted to obtain data on use and costs. British and Canadian studies were also used when data were otherwise unavailable. Data on physician, outpatient, clinic services, dental care,⁹ prescription medications,^{9,11} complementary and alternative therapies,¹²⁻¹⁸ behavioral therapies,¹⁹⁻²² hospital and emergency services,^{9,23} allied health, equipment and supplies, home health,⁹ and medically related travel⁹ were classified as direct medical. Data on child care,^{9,19} adult care,^{19,20} respite and family care,^{9,19,20}

home and care modifications,^{9,24} special education,^{19,20,25-27} supported employment,^{20,28-34} and other costs^{9,24} were classified as direct nonmedical. Although some dimensions of care may be misclassified between direct medical and direct nonmedical (for example, many special education programs provide behavioral therapies), because the degree of misclassification is not known, no corrections were made. Costs, as reported in the source materials, were inflated to 2003 US dollars using the all-item consumer price index.³⁵ State-specific costs were transformed to national averages³⁶ and foreign costs were converted to US costs using the latest available Federal Reserve exchange rates.³⁷ Use measures were translated to costs by multiplying the use measures by age group-specific survey-adjusted average costs from the MEPS.⁶ More in-depth information on how the cost estimates were constructed from these sources is available elsewhere¹ and in a technical appendix available on request.

Survey Analysis

Data from the NHIS⁷ and the MEPS⁶ were also used to supplement data on costs of autism and to also compute average costs for use in deriving the incremental costs of autism. Because confidentiality concerns constrain the MEPS to only report the first 3 digits of diagnosis codes, individuals with an *International Classification of Diseases, Ninth Revision (ICD-9)* diagnosis code of 299, which includes autism diagnoses (299.0x) as well as disintegrative psychoses (299.1x) and early childhood psychoses (299.8x/299.9x), were used as proxies for individuals with autism. Specific autism questions were available in the NHIS during 1997-2000. Information from those questions was combined with an ICD-9 diagnosis code of 299 in the NHIS and was linked to the MEPS to increase the number of usable cases. Survey-adjusted means for expenditures were then computed as described earlier. Further information is available elsewhere¹ and from the technical appendix.

INDIRECT COSTS

Productivity losses for people with autism were estimated by combining standard average work-life expectancies for all men and women taken from the economics literature (ages 23-57 years for men and 23-53 years for women),³⁴ with average income and benefits (from Tables 696 and 628 of the *Statistical Abstract of the United States*³⁶) and estimates of age- and sex-specific labor force participation rates.³⁸ Average incomes are projected for future years based on estimated productivity growth rates³⁵ to estimate average total earnings and benefits at each age. These estimates are adjusted for the fact that while some adults with autism are unable to work, others are (35% of adults with lower levels of disability and 10% of adults with higher levels of disability work in supported work environments). Finally, the lost value of sex-specific household services is added.^{3,39} These estimates do not account for the effects of taxes or lost leisure time. Similar methods were used to estimate productivity for parents. Fathers of children with lower levels of disability were assumed to be unemployed 10% of the time (and working full-time during the remaining 90%) and mothers were assumed to be unemployed 55% of time (and were working half-time 25% of the time and full-time, 20%).^{40,41} Fathers of children with higher levels of disability were assumed to be unemployed 20% of the time and mothers were assumed to be unemployed 60% of time (and were working half-time 30% of the time and full-time, 10%). These assumptions were combined with the same average earnings, benefits, productivity growth, labor force participation rates as used for individuals with autism, and the appropriate work-life expectancies. These estimates assumed households in which both a mother and a father care for 1 child with autism. These estimates will differ based on different family configurations.

Table 1. Age-Specific and Lifetime per Capita Incremental Societal Costs of Autism*

Age Group, y	Average Per Capita Cost per Age Group			Total Per Capita Cost
	Direct Medical	Direct Nonmedical	Indirect	
3-7	35 370	10 805	43 066	446 203
8-12	6013	15 708	41 138	314 297
13-17	5014	13 550	38 453	285 082
18-22	2879	10 720	36 090	248 446
23-27	1574	27 539	51 740	404 260
28-32	1454	23 755	35 757	304 828
33-37	1389	20 492	30 852	263 662
38-42	1283	17 676	29 132	240 457
43-47	1440	15 248	26 600	216 439
48-52	1447	13 152	24 531	195 650
53-57	1290	11 292	17 776	151 790
58-62	1218	9489	0	53 535
63-66	1027	7908	0	35 738
Total lifetime costs	305 956	978 761	1 875 667	3 160 384

*Costs presented in 2003 dollars. Costs for age 4 years and older are discounted to 2003 dollars using a discount rate of 3%. Life expectancy for men is age 66 years and for women, age 65 years.

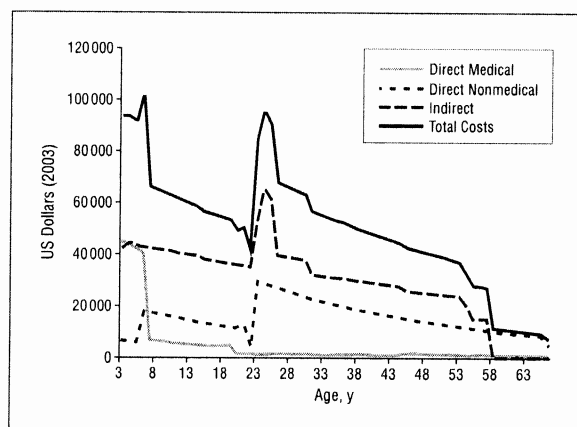


Figure 1. Age distribution of incremental societal costs of autism (present value).

CALCULATING COSTS

To the extent possible, cost estimates were derived for higher- and lower-functioning individuals as they were presented in the literature. Semidependent, independent, or those individuals described as having high-functioning autism were classified in the higher-functioning category. Dependent individuals or those not described as having high-functioning autism were classified in the lower-functioning category. Based on data presented in Fombonne,⁴² the prevalence of higher-functioning autism is assumed to be 54%. The male-female ratio is assumed to be 4:1. Weighted average per capita costs were computed based on the assumed distribution of lower- and higher-functioning status and the male-female ratio. Age 3 years was considered to be the baseline age (age at diagnosis) and 2003 was the baseline year. Because there is some evidence that people with autism have reduced life expectancies,⁴³⁻⁴⁶ costs were tabulated through age 66 years for males and through age 65 years for females. Costs were discounted to present value (to age 3 years) using a discount rate of 3% as recommended by the Panel on Cost-effectiveness in Health and Medicine.⁸ Costs in future years were discounted, or deflated, to reflect the time value of money: a dollar today is worth more

than a dollar in the future. In doing so, all costs were adjusted for the different periods in which they were incurred. In other words, dollars at different ages become comparable. Because health care resource investments, such as in the case of autism research and treatment budgets, incur costs in the present and potentially realize the benefits in the future, it is common to discount future flows of costs (and benefits) to present value. Although 3% is the currently used standard for a discount rate, this rate is varied in the sensitivity analyses described in the next subsection.

SENSITIVITY ANALYSES

In previous work, the robustness of the overall cost estimates was assessed using 1-way sensitivity analyses and conclusions were mostly robust to changes in many key parameters.¹ However, the total costs were found to be most sensitive to changes in the discount rate and to changes in the assumed level of indirect costs. Because variations in indirect costs will not substantially change the pattern of costs over the life cycle, herein focus is placed on the discount rate.⁸ The discount rate is varied between 2% and 5% as suggested by Gold et al.⁸

DEFINITION OF AUTISM

Many of the sources of data simply used the term *autism* and did not differentiate between the different autism spectrum disorders. Reflecting the literature, the term *autism* herein is used in an inclusive manner to mean all disorders in the spectrum. Given the nature of many of the nonmedical and indirect costs, it is likely that those costs are more representative of more disabled individuals. Older sources⁹ may have only included lower-functioning children and individuals in their definitions of autism. However, varying the proportions of lower- and higher-functioning individuals does not substantially change conclusions about overall lifetime costs.¹

RESULTS

In the Tables that follow, the average per capita costs by category are presented in 5-year intervals (the full Tables

Table 2. Age-Specific and Lifetime per Capita Incremental Societal Direct Costs of Autism*

Age Group, y	Average per Capita Cost per Age Group						
	Physician and Dental	Drugs	CAM Therapies	Behavioral Therapies	Emergency and Hospital	Home Health	Travel
3-7	1147	147	198	32 501	828	467	81
8-12	577	153	109	4033	768	303	70
13-17	435	131	50	3479	591	267	60
18-22	426	129	33	1254	852	132	52
23-27	496	124	28	0	774	106	45
28-32	507	114	25	0	682	87	39
33-37	547	98	21	0	598	93	33
38-42	540	84	18	0	522	90	29
43-47	765	72	16	0	426	137	25
48-52	845	61	14	0	352	154	21
53-57	851	52	12	0	292	65	18
58-62	810	44	10	0	323	14	16
63-66	632	34	9	0	301	39	14
Total lifetime costs	42 259	6180	2704	206 337	36 235	9738	2503

Abbreviation: CAM, complementary and alternative medicine.

*Costs presented in 2003 dollars. Costs for age 4 years and older are discounted to 2003 dollars using a discount rate of 3%. Life expectancy for men is age 66 years and for women, age 65 years.

Table 3. Age-Specific and Lifetime per Capita Incremental Societal Direct Nonmedical Costs of Autism*

Age Group, y	Average per Capita Cost per Age Group						
	Child Care	Adult Care	Respite Care	Home Improvements	Special Education	Supported Work	Other
3-7	4636	0	1100	161	4585	0	323
8-12	3999	0	948	139	10 343	0	278
13-17	3450	0	818	120	8922	0	240
18-22	2907	0	706	10	6247	0	851
23-27	0	25 064	0	9	0	836	1630
28-32	0	21 620	0	8	0	721	1406
33-37	0	18 650	0	7	0	622	1213
38-42	0	16 087	0	6	0	537	1046
43-47	0	13 877	0	5	0	463	903
48-52	0	11 970	0	4	0	399	778
53-57	0	10 326	0	4	0	291	672
58-62	0	8907	0	3	0	0	579
63-66	0	7423	0	3	0	0	483
Total lifetime costs	74 963	662 192	17 858	2388	150 483	19 349	51 528

*Costs presented in 2003 dollars. Costs for age 4 years and older are discounted to 2003 dollars using a discount rate of 3%. Life expectancy for men is age 66 years and for women, age 65 years.

are available as eTables 1-4 at <http://archpediatrics.com>). **Table 1** and **Figure 1** display the incremental societal direct medical, direct nonmedical, and indirect costs. Direct medical costs are quite high for the first 5 years of life (average of around \$35 000), start to decline substantially by age 8 years (around \$6000), and continue to decline through the end of life to around \$1000. Direct nonmedical costs vary around \$10 000 to approximately \$16 000 during the first 20 years of life, peak in the 23- to 27-year age range (around \$27 500), and then steadily decline to the end of life to around \$8000 in the last age group. Indirect costs also display a similar pattern, decreasing from around \$43 000 in early life, peaking at ages 23 to 27 years (around \$52 000), and declining through the end of life to \$0.

Table 2 displays the individual components of the incremental societal direct medical costs. Considered over the entire life span, direct medical costs make up 9.7% of total discounted lifetime costs. Behavioral therapies, which are the largest component of direct medical costs, make up 6.5% of total discounted lifetime costs.¹ However, behavioral therapies, as presented herein, are only relevant for children 19 years or younger. The large direct medical costs early in life are driven primarily by behavioral therapies that cost around \$32 000 during the first 5-year age group and decline from about \$4000 in the 8- to 12-year age group to around \$1250 for the 18- to 22-year age group. Physician and dental costs are initially high, then decrease, but increase again in later life. Prescription drugs, complementary and alternative therapies, and hospital and emergency services are also relatively

Table 4. Age-Specific and Lifetime per Capita Incremental Societal Indirect Costs of Autism*

Age Group, y	Average per Capita Cost per Age Group	
	Own Indirect	Not Own Indirect
3-7	0	43 066
8-12	0	41 138
13-17	0	38 453
18-22	0	36 090
23-27	32 703	19 036
28-32	32 620	3136
33-37	30 852	0
38-42	29 132	0
43-47	26 600	0
48-52	24 531	0
53-57	17 776	0
58-62	0	0
63-66	0	0
Total lifetime costs	971 072	904 595

*Costs presented in 2003 dollars. Costs for age 4 years and older are discounted to 2003 dollars using a discount rate of 3%. Life expectancy for men is age 66 years and for women, age 65 years.

high initially but steadily decline. Some costs decline less smoothly than others because of different availability of cost-by-age estimates in the literature.

Table 3 displays the individual components of the incremental societal direct nonmedical costs. Nonmedical costs, except during ages 3 to 7 years, are more expensive than direct medical costs and make up 31% of total discounted lifetime costs.¹ Different costs become relevant at different ages, which contributes to the dips and spikes in the direct nonmedical line in Figure 1. Child care and respite costs, which average about \$5700 in early ages to around \$3600 at ages 18 to 22 years, contribute far less (3% of total discounted lifetime costs) than adult care costs (21% of total discounted lifetime costs), which range from around \$25 000 at ages 23 to 27 years to around \$7400 at ages 63 to 66 years. Special education costs, which make up 4.8% of total discounted lifetime costs, range from around \$12 000 at age 6 years (costs for ages 3-5 years are assumed to be zero) to around \$6200 at ages 18 to 22 years, and supported employment costs range from around \$800 at ages 23 to 37 years to around \$300 at ages 53 to 57 years (age 57 years is the assumed end of working life).

Table 4 displays the components of the incremental societal indirect costs. Indirect costs are by far the largest component of the total incremental societal costs of autism (59.3% of total discounted lifetime costs).¹ Own indirect costs, which make up 30.7% of total discounted lifetime costs, range from around \$33 000 at ages 23 to 27 years to around \$18 000 at ages 53 to 57 years. Not own (assumed herein to be parents') indirect costs, which make up 28.6% of total discounted lifetime costs, range from around \$43 000 at ages 3 to 7 years, when parents are assumed to be about 33 to 37 years of age, to around \$19 000 at ages 23 to 27 years, when parents are assumed to be 53 to 57 years of age, to around \$3000 per year for the next 5 years until the end of the average work life. Although total indirect costs spike at ages 23

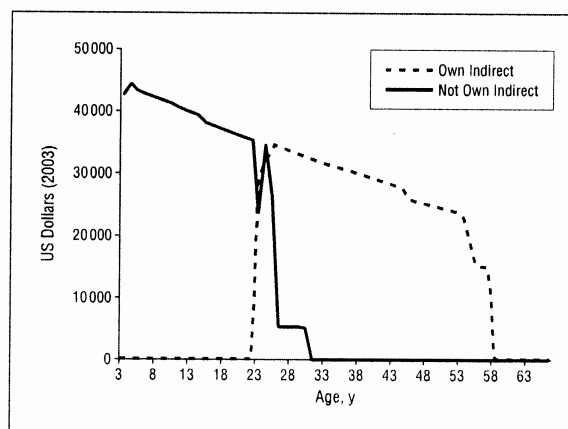


Figure 2. Age distribution of own and not own indirect incremental costs (present value).

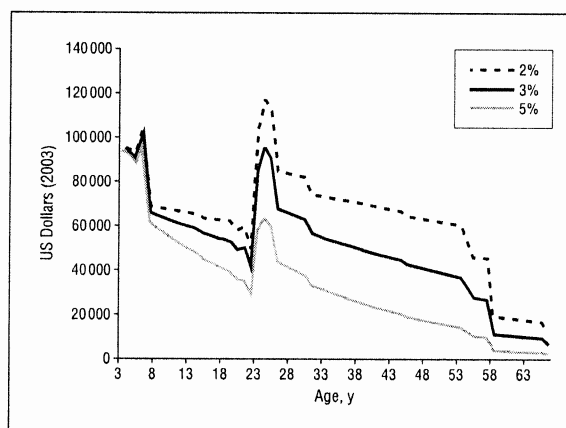


Figure 3. Age distribution of total incremental societal costs of autism computed at different discount rates.

to 27 years, because of the overlapping own and not own indirect costs, as **Figure 2** indicates, at any given time from age 3 years through age 57 years, there is a substantial and smoothly declining level of indirect costs. Figure 2 also dramatically illustrates, at least for this model, the transition from exclusive parental lost productivity almost immediately to lost own productivity.

SENSITIVITY ANALYSES

Sensitivity analyses using 2% and 5%, which are common upper and lower bounds, reveal that the patterns of age-specific expenditures are similarly shaped. **Figure 3** displays total costs using 2%, 3%, and 5% as the discount rates. There is an inverse relationship between the discount rate and the weight placed on future costs: lower discount rates place greater weight on future costs and higher rates place less weight on future costs. As a result, total present value costs will be larger the smaller the discount rate. The maximum difference in total costs between the 5% scenario and the 2% scenario (about \$53 000) occurs at age 24 years and the average difference in costs between the 5% and 2% scenarios is about \$31 000.

This article presents the first description, to my knowledge, of the societal costs of autism in the United States across all ages of the life span and contributes not only to the literature on the costs of autism but also to the literature on age-specific health care costs in general. As was previously reported, the total annual societal per capita cost of caring for and treating a person with autism in the United States was estimated to be \$3.2 million and about \$35 billion for an entire birth cohort of people with autism.¹ Sensitivity analyses revealed that these lifetime costs could range from \$13 billion to \$76 billion depending on the underlying assumptions of the model. Although those estimates are highly conservative because they exclude a number of important elements (such as legal costs that families incur to secure services^{47,48}, lost productivity of those other than parents; the costs of genetic testing; the full costs of alternative therapies, including diets; the costs of adverse outcomes of potentially dangerous treatment modalities; and costs associated with immunization-avoidance behaviors⁴⁸), they are valuable because they add information to a relatively underdeveloped literature. As treatment and, perhaps prevention, strategies are developed, knowledge of when costs are incurred relative to when benefits are expected is important for clinical decision-making and cost-effectiveness analysis efforts.

Knowledge about age-specific per capita incremental societal costs is particularly important because, as opposed to the summary lifetime data presented previously,^{1,25,47} age-specific data illuminate the relative magnitudes of different types of costs at different ages. Given that at different ages different segments of society are responsible for absorbing these costs, this detailed disaggregation of costs can provide even more valuable information to planners, policy makers, and even to families making decisions that can affect current and future financial health, especially as they consider the fact that at various points in the life cycle different costs are more germane than others.

Although autism is typically thought of as a disorder of childhood, its costs can be felt well into adulthood. Adult care, which has the largest lifetime cost of all direct costs, is typically more than 5 times larger than the next 3 largest costs, which include care incurred during childhood (behavioral therapies, child/respite care, and special education). Alemayehu and Warner⁴⁹ reported that the typical American spends about \$317 000 over his or her lifetime in direct medical costs, incurring 60% of those costs after age 65 years. In contrast, people with autism incur about \$306 000 in incremental direct medical costs, implying that people with autism spend twice as much as the typical American over their lifetimes and spend 60% of those incremental direct medical costs after age 21 years.

These results, especially on the substantial costs resulting from lost productivity of both individuals with autism and their parents and from rather large adult care costs, have important implications for those aging mem-

bers of the baby boom generation approaching retirement. As those individuals retire, many of their adult children with autism will be transitioning into adult care settings. Those costs, combined with very limited to nonexistent income for their adult children with autism combined with potentially lower levels of savings because of decreased income and benefits while employed, may create a large financial burden affecting not only those families but potentially society in general. Perhaps physicians and other care professionals should consider recommending that parents of children with autism seek financial counseling to help plan for the transition into adulthood.

Although this study is limited by a number of factors, it is the first of its kind, to my knowledge, and can shed insight into the lifetime distribution of autism costs and also motivate future, more rigorous studies. The cost model presented herein is based on a number of simplifying assumptions and relies on sometimes incomplete and old information. These caveats should be kept in mind when using these estimates for policy or practice decision making. The results presented herein for direct medical costs are consistent with recently published data on health care use and costs for children with autism. Gurney et al⁵⁰ reported that, relative to children without autism, children with autism, as reported by their parents, experience a significantly higher number of preventive visits and emergency and nonemergency hospital visits. Croen et al⁵¹ reported, based on administrative data from the Northern California Kaiser Permanente Medical Care program, that children with autism incurred 2.5 times as much outpatient costs, 2.9 times as much inpatient costs, and 7.6 times as much medication costs as randomly selected children without autism. Pursuing a research agenda of both carefully and systematically documenting the costs of autism in the United States can be helpful in improving these estimates. Prospectively tracking the life experiences of individuals with autism and their families and obtaining a wide variety of data on the different sources of services for people with autism can provide this more complete picture. Prospectively collected clinical and quality-of-life data combined with cost data will be even more useful for understanding the societal costs, both financial and nonfinancial, of caring for those members of our society with autism at every age of the life course.

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Additional Information: eTables 1-4 are available at <http://archpediatrics.com>.

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