The Costs of Autism
Technical Appendix

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1. Introduction

This document contains a description of the model used to calculate the total societal costs of autism presented in Chapter 20 of Understanding Autism: From Basic Neuroscience to Treatment [1] and in the article The Lifetime Distribution of the Incremental Societal Costs of Autism.[2] It also contains a detailed list of data sources and assumptions that underlie this model. As described in the Chapter, in the process of assembling the disparate pieces of information gathered from difference sources into one national estimate for presentation to a wide audience, certain simplifying assumptions were made. Electronic spreadsheet files that implement this model and present how these assumptions are used are also available from the author.

Each section of this appendix explains how each cost component and probability parameter were extracted from the source literature and describes which decisions and assumptions were made to use these data points. The sections describing the costs will be organized by the order of the cost components as they appear in the Chapter. Additional sections explaining other parameters will follow.

2. Direct Medical Costs

2.1. Physician, Outpatient, and Clinic Services

The cost at each age was computed as the average of the costs presented by Birenbaum[3] and the costs computed from my NHIS-MEPS analysis minus the overall physician costs derived from MEPS.

2.2. Dental

The cost at each age was computed as the average of the costs presented by Birenbaum[3] and the costs computed from my NHIS-MEPS analysis minus the overall dental costs derived from the MEPS.

2.3. Medications

The cost at each age was computed as the average of the costs presented by Birenbaum[3] and the costs computed by the Medications Worksheet (see below). This average did not need to be adjusted to obtain incremental costs.

2.3.1. Medications Worksheet

The proportions of children and adults using various psychotropic drugs were taken from the literature[4, 5] and vary by age and level of disability. The age- and disability-specific average costs of anti-depressants, stimulants, neuroleptics, and sedatives were derived using the NHIS-MEPS data. The products of the probability of use of each of these medications times their average costs were summed to provide the disability- and age-specific costs.

2.4. Complementary and Alternative Medicine

The cost at each age was computed using data from the literature on the prevalence of CAM use among people with autism and data on the costs of CAM therapies. These costs did not need to be adjusted to obtain incremental costs.

The average cost of CAM therapies ($388=average of $764 in Eisenberg[6] and $101 in Yussman[7]) was multiplied by the age- and disability specific prevalence rates of CAM usage that were derived from Green[8], Langworthy-Lam,[9] Aman,[10] and Nickel.[11] These rates were further adjusted by the CAM prevalence among those with low and high disability derived from Green[8] and the CAM prevalence distribution derived from Langworthy.[9] Refer to the CAM worksheet for computational details.

2.5. Therapies/Behavioral Support

Costs from Jacobson[12] and Hildebrand[13] were averaged for ages 3-6. Data for ages 6-19 were taken from Hildebrand.[13] These costs did not need to be adjusted to obtain incremental costs.

2.6. Hospital Services/Emergency Department

Hospital and emergency department costs are computed as the average of the costs presented in Birenbaum,[3] my NHIS-MEPS analyses, and in Walsh.[14] Because the costs presented in Walsh[14] are based on a sample that contains individuals with mental retardation as well as individuals with autism, those cost estimates are higher than the estimates would be if the sample consisted only of people with autism. The ratio of hospital costs for people with autism to people with severe mental retardation in the Birenbaum study is 0.59:1 (=$1,000÷$1,700). Using that ratio, the Walsh estimates are adjusted downward to $1,949, $2,038, and $4,786.

2.7. Allied Health, Equipment, Home Health

The cost at each age was computed by adding the costs of allied health, supplies, and equipment from Birenbaum plus the costs of home health derived from analysis of the NHIS-MEPS data. Overall home health costs were then subtracted to derive the incremental costs.

2.8. Medically-related Travel

The cost at each age was come directly from Birenbaum.[3]

3. Direct Non-Medical Costs

Non-medical costs included costs required to care for people with autism that are not medical in nature nor are provided by medical personnel. There may, however, be some overlap, and hence misclassification, in some cases. For example, some behavioral therapy services (medical) may be delivered as part of special education services (non-medical).

3.1. Child care

The cost at each age through 22 was computed as the average of the costs presented by Birenbaum[3] and Hildebrand[13] minus the average annual household expenditure on child care ($3,588) [15] per year. These costs vary by disability.

3.2. Adult Care

The cost at each starting at 23 was computed as the average of the 4 costs presented in Hildebrand[13] and Jacobson[12] (day programs, home/community services, institutional services, and residential placement services). The cost for residential services was computed as $p(X)+(1-p)(Z)$, where p=the proportion of adults living at home (=0.50 in the base case), X=51,175 (costs for those living at home), and Z=73,108 (the cost for those in a group home). These costs did not need to be adjusted to obtain incremental costs.

3.3. Respite Care/Family Support

The costs at each age through 22 were computed as the average of the costs presented by Birenbaum,[3] Hildebrand,[13] and Jacobson[12]. These costs did not need to be adjusted to obtain incremental costs.

3.4. Home/Car Modifications

The costs at each age come directly from Birenbaum.[3]

3.5. Special Education

Special education costs for low and high disability children are computed as the average of special education costs given by Jacobson,[12] Hildebrand,[13] and the Center for Special Education Financing (CSEF)[16] minus the cost of regular education reported by CSEF ($4,854). These disability-specific costs are then adjusted, weighted, and averaged to derive the average cost of special education for children with autism. The total age-specific special education costs are defined as p(L)+(1-p)(H) where p=proportion of children with low disability, L=cost for children with low disability=(% of children with low disability in low-cost special education × low-cost special education) + (% of children with low disability in high-cost special education × high-cost special education) + (% of children with low disability in regular education × regular-education cost). H is defined similarly for children with high levels of disability. For these analyses, I assume that the low-cost special education (geared toward students with low levels of disability) is the same cost as regular education and that the high-cost education (geared toward students with high levels of disability) is simply special education, whose cost is given by CSEF (Exhibit 11-8, Page 28). The proportion of low disability children in low-cost special education (80%), of low disability children in high-cost special education (0%), of low disability children in regular education (20%), of high disability children in low-cost special education (0%), of high disability children in high-cost special education (100%), and of high disability children in regular education (0%) were derived from Järbrink.[17]

3.6. Supported Employment

The cost of supported employment is computed as the difference between average per person program costs (derived from Rusch,[18] Mawhood,[19] the Bureau of Labor Statistics,[20] and Keel[21]) and supported work income, multiplied by the proportion of autistic adults that are in a supported employment context. Specifically, the cost of supported employment=((average per person program costs including the cost of an occupational therapist) – supported employment income) × the proportion of adults with autism in supported employment.

3.7. Other

The costs at each age through 20 were taken directly from Birenbaum. Starting at 21, the costs were computed as the average of the costs presented by Birenbaum and Fujiura. These costs did not need to be adjusted obtain incremental costs. In the original computations of this model that were published in the chapter and in the Archives of Pediatrics and Adolescent Medicine, Fujiura's cost of other non-medical services was entered in the model as $5,900 rather than $8,315. Therefore the values for direct non-medical costs and for the total costs in the publicly available spreadsheets will differ slightly from the published estimates.

4. Indirect Costs

Indirect costs were computed using a human capital approach[22, 23] and combine data on average earnings, benefits, and household services with information on average work life expectancies and labor force participation rates to derive an estimate of what the average person would have earned. In the case of people with autism, these hypothetical earnings are then adjusted for the fact that some portion of adults with autism do work (supported employment). In the case of parents, assumptions are made about reductions in work to derive the value of lost productivity.

4.1. Own Lost Productivity

Own lost productivity (own indirect cost) is calculated in a number of steps. First, income for the average person is calculated. The sum of current and projected (Congressional Budget Office)[24] base salary, benefits (which is a percentage of base salary taken from the Statistical Abstract of the United States[25]), and household production (see below)[26] is multiplied by current and projected labor force participation (LPF) rates to give the sex- and age-specific base incomes for the average person. Second, the value of supported work income is calculated. It is equal to base salary multiplied by the proportion of regular hours worked while in a supported employed context multiplied, in turn, by the fraction of average income that is earned in a supported employed context. Finally, the productivity loss is calculated as the sum of average earnings for those not in supported employment plus the average earnings less supported work earning for those in supported employment. In other words (1-p)(I)+(p)(I-S) where p=proportion of adults with autism who were in supported employment, I=average income, and S=supported income.

4.2. Parents' Lost Productivity

Parents' lost productivity is the sum of fathers' and mothers' lost productivity. Average sex- and age-specific earnings (base salary plus benefits) were calculated in a similar manner to own lost productivity. The average earnings are then adjusted down by making assumptions about the proportion of mothers and fathers who are working full time, half time, or are unemployed due to a child with autism. Based on data presented in Järbrink and in Birenbaum, fathers of autistic children with low (high) levels of disability are unemployed 0% (20%), employed full-time 90% (80%), and employed half-time 10% (0%) of the time and mothers are unemployed 55% (60%), employed full-time 25% (30%), and employed half-time 20% (10%) of the time. Unemployed parents earn nothing and half-time parents earn 50% of the average total earnings.

4.3. Lost Household Production

To estimate the value of lost household production associated with decreased autism-related productivity I used the average of total lost services for the husband/wife, father, mother/father categories of Table 4 in Tinari[26] (rows 1, 3, and 4) to estimate lost household productivity for males and the husband/wife, mother, mother/father categories (rows 1, 2, and 4) to estimate lost household productivity for females.

5. Other Assumptions and Parameters

A number of other assumptions needed to be made, which were all drawn from the literature, to complete the model

5.1. Conversions of Costs to 2003 Dollars

Costs that were presented in years prior to 2003 were converted to 2003 dollars using the CPI calculator available on the BLS website (http://data.bls.gov/cgi-bin/cpicalc.pl) or in the CPI Calculator spreadsheet.

5.1.1. Conversion from State-Specific Costs

Costs that were specific to one state were first inflated to 2003 dollars and then converted to national costs estimates using Table 699 of the 2004 Statistical Abstract of the United States.[25] I used the all item price index for the metropolitan area whose state matched the state that needed to be converted.

5.1.2. Conversions from Foreign Currencies

Costs from other countries were first converted to dollars using the latest available exchange rate for the given year using data from the Federal Reserve Historical Data.[27] The resulting dollar amount was then converted to 2003 dollars.

5.2. CPI growth

Data from the Congressional Budget Office (Table 2-1 located at: http://www.cbo.gov/showdoc.cfm?index=4493&sequence=3) were used to predict CPI growth when needed by the model.

5.3. Labor Productivity growth

Data from the Congressional Budget Office (Table 2-4 located at: http://www.cbo.gov/showdoc.cfm?index=5773&sequence=3) were used to predict future increases in labor productivity (salaries) for the indirect cost spreadsheets.

5.4. Discount Rate

The discount rate, used to compute the present value of future costs, was set to 3% as recommended by Gold et al.[23]

5.5. Perspective

Given the broad nature of autism in terms of its impact not only on families, but schools, social service agencies, and even employers, and because there is considerable public funding for supporting individuals with autism, a societal perspective will be taken. The Panel on Cost-effectiveness in Health and Medicine recommends the use of the societal perspective.[23] No attempt was made to separate costs by source of payment.

5.6. Incremental Costs

The societal costs of autism should reflect the incremental cost over and beyond those costs absent autism. In other words, costs for above and beyond the costs of people without autism. When possible those incremental costs are taken directly from the source materials. When costs are not reported as incremental costs, I subtracted national average costs data for the appropriate category, including using age group-specific average costs for medical services derived from my analysis of the MEPS data.

5.7. Labor Force Participation Rates

Data on the current and future projected sex-specific labor force participation rates from the Congressional Budget Office (Table 1 located at: (http://www.cbo.gov/showdoc.cfm?index=5803&sequence=0) were used to predict future productivity losses.

5.8. Proportion of High/Low Disability

The proportion of people with low disability autism (0.54 in the base model) was computed by taking the average of the proportions of normal IQ in Table 4 of Fombonne (2003).[28]

5.9. Proportion of Adults with Autism Living at Home

The proportion of adults with autism living at home (currently assumed to be 50%) is based on information in Hildebrand (page 6).[13]

5.10. Sex ratio

Contains the ratio of male to female with autism. Assumed to be 4:1 based on the consensus value in the literature.

5.11. Employment and Supported Employment Parameters

To fully compute lost productivity a number of parameters beyond average age are needed. The value of household production was taken from the forensic economics literature[26] and the value of fringe benefits (29% of earned salary) was taken from Table 628 of the 2004 Statistical Abstract of the United States. Average work life expectancies at age 23 (until 57 years of age for men and 53 years of age for women) were also taken from the forensic economics literature.[29]

The proportion of adults working in supported employment context (35% for low disability and 10% for high disability) and the proportion of hours worked (75% of the average number of hours) are taken from Mank.[30] The proportion of income earned (20% of average earning) is taken from Jacobson, and the number of occupational therapists per person in supported employment (3) is taken from Keel.[21] The estimated salary and benefits of the average occupational therapist, as suggested by Capo,[31] was taken from the Bureau of Labor Statistics' Occupational Outlook Handbook[20] and Table 628 of the 2004 Statistical Abstract.[25]

5.12. Population Parameters

5.12.1. Life Expectancy

Based the work of Shavelle and Strauss, I assume that males have a live expectancy of 66 years and females have a life expectancy of 65 years.[32]

5.12.2. Prevalence of Autism

The prevalence rate of autism assumed for the base case of the model (27.5 per 10,000) is taken from Fombonne (2003).[28]

5.12.3. US Population Of 3-Year Old Children

Based on data from the US Census Department,[33] US vital statistics,[34] and Fombonne[28] I assume that there are 4 million 3-year old children in the United States in 2003. When multiplied by the prevalence rate, the assumed incident cohort of children with autism in 2003 contains 11,000 children.

Table 1. Sources for Direct Medical Costs

Category	Author	Age	High/Low Disability	Year	Cost	2003 Cost ($)
Physician	Birenbaum	0-17	All	1985	300	513
Physician	Birenbaum	18-24	All	1985	259	443
Physician	NHIS/MEPS					See Table 2.
Dental	Birenbaum	0-17	All	1985	50	86
Dental	Birenbaum	18-24	All	1985	60	103
Dental	NHIS/MEPS					See Table 2.
CAM Therapies	See CAM Therapies Table					See Table 3.
Medication	Birenbaum	0-17	All	1985	100	171
Medication	Birenbaum	18-24	All	1985	160	273
Medication	See Medication Therapies Table					See Table 4.
Therapies/Behavioral Support	Hildebrand	3-6	All	2000	65,000 Canada	46,316 (45,053 was used in error)
Therapies/Behavioral Support	Hildebrand	6-19	Low	2000	5,810 Canada	4,140
Therapies/Behavioral Support	Hildebrand	6-19	High	2000	8,300 Canada	5,914
Therapies/Behavioral Support	Jacobson	3-6	All	1996	32820 Pennsylvania	37,537
Hospital/Emergency	Birenbaum	0-17	All	1985	350	599
Hospital/Emergency	Birenbaum	18-25	All	1985	1,175	3,037
Hospital	Walsh	0-21	All	1991	3,303 × 0.59=1,949	2,636
Hospital	Walsh	22-55	All	1991	3,454 × 0.59=2,038	2,757
Hospital	Walsh	56-85	All	1991	8,112 × 0.59=4,786	6,473
Hospital	NHIS/MEPS					
Travel	Birenbaum	All	All	1985	50	86
Allied Health	Birenbaum	0-17	All	1985	150	257
Allied Health	Birenbaum	18-24	All	1985	100	171 (195 used in error)
Equipment	Birenbaum	0-17	All	1985	20	34
Equipment	Birenbaum	18-24	All	1985	6	10
Supplies	Birenbaum	0-17	All	1985	50	86
Supplies	Birenbaum	18-	All	1985	10	17

Category	Author	Age	High/Low Disability	Year	Cost	2003 Cost ($)
		24				
Home Health	NHIS/MEPS					See Table 2.
Other	Birenbaum	All	All	1985	200	342

Table 2. Costs Derived from the NHIS/MEPS for Autistic Individuals

Age	Physician Visits	Hospital + Emergency	Home Health	Dental
0-5	2,894	619	239	57
6-17	1,044	81	43	754
18-24	1,456	182	11	257
25-34	2,598	437	15	263
35-44	3,771	595	111	465
45-54	7,190	649	478	1,131
55-64	10,472	2,092	312	652
65-74	8,908	3,433	691	963
75-max	9,787	5,193	17,460	0

Table 3. Summary Data on Prevalence and Cost of CAM Therapies

	Low Disability		High Disability	
Age	Prevalence	Cost	Prevalence	Cost
0-6	0.52	$201.30	0.67	$258.72
7-13	0.31	$118.71	0.39	$152.58
14-20	0.12	$48.17	0.16	$61.92
21+	0.12	$48.17	0.16	$61.92

Table 4. Prevalence and Cost of Medications

	Anti-Depressants			Stimulants			Neuroleptics (Anti-Psychotics)			Sedatives		
	Prevalence		Cost	Prevalence		Cost	Prevalence		Cost	Prevalence		Cost
Age	Low	High		Low	High		Low	High		Low	High	
0-5	0.05	0.3	123	0.07	0.2	172	0.07	0.27	353	0.05	0.08	42
6-17	0.05	0.3	349	0.07	0.2	311	0.07	0.27	630	0.05	0.08	58
18-24	0.05	0.3	328	0.07	0.2	204	0.07	0.27	445	0.05	0.08	15
25-34	0.05	0.3	404	0.07	0.2	164	0.07	0.27	891	0.05	0.08	53
35-44	0.05	0.3	472	0.07	0.2	205	0.07	0.27	696	0.05	0.08	149
45-54	0.05	0.3	452	0.07	0.2	216	0.07	0.27	677	0.05	0.08	50
55-64	0.05	0.3	422	0.07	0.2	164	0.07	0.27	666	0.05	0.08	76
65-74	0.05	0.3	310	0.07	0.2	160	0.07	0.27	209	0.05	0.08	122
75-max	0.05	0.3	305	0.07	0.2	140	0.07	0.27	293	0.05	0.08	105

Table 5. Source for Direct Non-Medical Costs

Category	Author	Age	High/Low Disability	Year	Cost	2003 Cost ($)
Child Care	Birenbaum	0-17	All	1985	250	428
Child Care	Birenbaum	18-24	All	1985	50	86
Respite	Birenbaum	All	All	1985	10	17
Special Programs	Birenbaum	0-17	All	1985	200	342
Other	Fujuira	21+	All	1990	5,900	8,315 (5,900 used in error)
Child Care	Hildebrand	3-22	Low	2000	6,720 Canada	4,788
Child Care	Hildebrand	3-22	High	2000	9,600 Canada	6,841
Placement	Hildebrand	3-19	Low	2000	22,680 Canada	16,161
Placement	Hildebrand	3-19	High	2000	32,400 Canada	23,087
Day Program	Hildebrand	23+	Low	2000	18,480 Canada	13,168
Day Program	Hildebrand	23+	High	2000	36,400 Canada	25,937
Home/Community Services	Jacobson, Mulick	22-55	Low	1996	31,818 Pennsylvania	36,394
Home/Community Services	Jacobson, Mulick	22-55	High	1996	46,838	53,574
Institutional Services	Jacobson, Mulick	23+	All	1996	56,775 Pennsylvania	66,448
Residential	Hildebrand	19+	Low (living at home)	2000	71,820 Canada	51,175
Residential	Hildebrand	19+	High (in group home)	2000	102,600 Canada	73,108
Respite	Hildebrand	6-19	Low	2000	2,590 Canada	1,846
Respite	Hildebrand	6-19	High	2000	3,700 Canada	2,636
Respite	Jacobson, Mulick	0-17	All	1996	1,110 Pennsylvania	1,258
Special Education	Jacobson, Mulick	6-21	Low	1996	12,935 Pennsylvania	15,138
Special Education	Jacobson, Mulick	6-21	High	1996	28,806	33,713
Special Education	Hildebrand	6-19	Low	2000	27,650 Canada	19,702
Special Education	Hildebrand	6-19	High	2000	39,599 Canada	28,216
Regular Education	Center for Special Education Finance	7-21	N/A	2002	4,745	4,854
Special Education	Center for Special Education Finance	< 22	N/A	2002	8,310	8,501
Supported Employment	Mawhood	>22	All	1999	2,473 United	4,412

Category	Author	Age	High/Low Disability	Year	Cost	2003 Cost ($)
					Kingdom	
Supported Employment	Rusch	>22	All	1993	11,500 Illinois	11,469
Home/Car Modifications	Birenbaum	0-17	All	1985	100	171
Home/Car Modifications	Birenbaum	18-24	All	1985	10	17

Table 6. Spreadsheets needed for calculations

Name of Spreadsheet	Description	Uses…	Used by…
Cost of Reg Ed	Contains the assumed yearly cost of regular education	N/A	Spec Ed LO Spec Ed HI Spec Ed
CPI Growth	Contains projected changes in CPI and M-CPI from CBO	N/A	Final Results
CAM	Calculates the costs of CAM therapies from multiple sources	N/A	Direct medical HI Direct medical LO
Direct medical HI	Contains data on all categories of direct medical costs for high disability from literature and MEPS analyses	Rx CAM	Final Results
Direct medical LO	Contains data on all categories of direct medical costs for low disability from literature and MEPS analyses	Rx CAM	Final Results
Direct non-medical HI	Contains data on all categories of direct non-medical costs for high disability from literature	Spec Ed Suppt Work	Final Results
Direct non-medical LO	Contains data on all categories of direct non-medical costs for low disability from literature	Spec Ed Suppt Work	Final Results
Discount rate	Contains discount rate used	N/A	Final Results
Final Results	Combines results from all spreadsheets with assumed values of the population size of 3 year olds and autism prevalence rates	Direct Medical LO Direct Medical HI Direct Non-Medical LO Direct Non-Medical HI Percent LO CPI Growth Discount Rate Sex Ratio Indirect	N/A
Growth rates	Contains projected changes in CPI and LFP rates from CBO	N/A	Indirect Own Indirect Not Own
Indirect Not Own	Contains calculations for parents' lost productivity; contains assumed values of % of parents employment efforts (full-, part-time, and unemployed)	LFP Rates Growth Rates	Indirect

Name of Spreadsheet	Description	Uses…	Used by…
		Supptd Work Income	
Indirect Own	Contains calculations for own lost productivity	LFP Rates Growth Rates Supptd Work Income Suppt Work	Indirect
Indirect	Summarized data from Indirect Own and Indirect Now Own	Indirect Not Own Indirect Own	Final Results
LFP Rates	Contains projected labor force productivity rates from CBO	N/A	Indirect Own Indirect Not Own
NHIS-MEPS Summary	Contains results of NHIS-MEPS analyses	N/A	
Percent LO	Contains assumed proportion of cases with ASD with lower levels of disability	N/A	Spec Ed Final Results
Rx	Contains estimates of prescription drug expenses from literature and from MEPS analyses	N/A	Direct Medical LO Direct Medical HI
Sex Ratio	Contains assumed sex ratio	N/A	Final Results
Spec ed HI	Contains values of special education costs from literature for "HI" cases	Cost of Reg Ed	Spec Ed
Spec ed LO	Contains values of special education costs from literature for "LO" cases	Cost of Reg Ed	Spec ED
Spec ed	Contains the summary costs of special education; also contains assumed values of % of LO and HI in special and regular education	Cost of Reg Ed Percent LO Spec Ed LO Spec Ed HI	Direct Non-Medical LO Direct Non-Medical HI
Suppt Work	Contains cost of supported work programs for LO and HI men and women	Supptd Work Income	Direct Non-Medical LO Direct

Name of Spreadsheet	Description	Uses…	Used by…
			Non-Medical HI Indirect Own
Supptd Work Income	Contains data on % LO and HI in supported work, % of hours worked, % of income earned, % of salary due to benefits, # of adults served by an occupational therapist, and values for men and women of base income, and value of household productivity	N/A	Suppt Work Indirect Own Indirect Not Own

Other Spreadsheets:

Cost Calculator Using CPI – calculator to inflate previous years dollar amounts into 2003 values based on all item CPI or medical CPI

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