Original Investigation

Costs of Autism Spectrum Disorders in the United Kingdom and the United States

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IMPORTANCE The economic effect of autism spectrum disorders (ASDs) on individuals with the disorder, their families, and society as a whole is poorly understood and has not been updated in light of recent findings.

OBJECTIVE To update estimates of age-specific, direct, indirect, and lifetime societal economic costs, including new findings on indirect costs, such as individual and parental productivity costs, associated with ASDs.

DESIGN, SETTING, AND PARTICIPANTS A literature review was conducted of US and UK studies on individuals with ASDs and their families in October 2013 using the following keywords: *age, autism spectrum disorder, prevalence, accommodation, special education, productivity loss, employment, costs,* and *economics*. Current data on prevalence, level of functioning, and place of residence were combined with mean annual costs of services and support, opportunity costs, and productivity losses of individuals with ASDs with or without intellectual disability.

EXPOSURE Presence of ASDs.

MAIN OUTCOMES AND MEASURES Mean annual medical, nonmedical, and indirect economic costs and lifetime costs were measured for individuals with ASDs separately for individuals with and without intellectual disability in the United States and the United Kingdom.

RESULTS The cost of supporting an individual with an ASD and intellectual disability during his or her lifespan was $2.4 million in the United States and £1.5 million (US $2.2 million) in the United Kingdom. The cost of supporting an individual with an ASD without intellectual disability was $1.4 million in the United States and £0.92 million (US $1.4 million) in the United Kingdom. The largest cost components for children were special education services and parental productivity loss. During adulthood, residential care or supportive living accommodation and individual productivity loss contributed the highest costs. Medical costs were much higher for adults than for children.

CONCLUSIONS AND RELEVANCE The substantial direct and indirect economic effect of ASDs emphasizes the need to continue to search for effective interventions that make best use of scarce societal resources. The distribution of economic effect across many different service systems raises questions about coordination of services and sectors. The enormous effect on families also warrants policy attention.

Editorial

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Autism spectrum disorder (ASD) is a neurodevelopmental disorder associated with impaired social ability, especially communication, and restricted, repetitive patterns of behavior, interests, or activities. Autism spectrum disorder can be associated with significant functional impairments and long-term health, social, and financial costs for individuals with ASDs, their families, and society as a whole.[1] The increase in the number of individuals diagnosed as having ASDs[2-4] and ensuing discussions regarding personal, family, and societal responsibilities emphasize the urgent need for accurate estimates of the economic effect of ASDs.

Most previous studies of costs associated with ASDs provide estimates within particular domains, primarily health care, but the overall economic effect of ASDs is not well established. The most recent comprehensive estimates of costs associated with ASDs were published in 2006 for the United States[5] and 2009 for the United Kingdom[6]; both studies needed to rely on many assumptions about prevalence and costs for which no published data existed. Since then, studies have provided more accurate estimates of costs in various domains, such as individual and parental productivity loss.[7,8] We therefore provide new estimates of the costs of ASDs for the United States and the United Kingdom. Our study differs from previous research in 3 ways: we provide more comprehensive estimates of costs associated with ASDs, we offer estimates for 2 countries, and we separate individuals with and without intellectual disability (ID), an important distinction given that cognitive impairments, separate from impairments associated with ASDs, may significantly influence costs.

Methods

New estimates of prevalence and some costs were obtained through a literature review conducted in 2013 concentrating on UK and US studies using *age, autism spectrum disorder, prevalence, accommodation, special education*, and *productivity loss* as keywords. Availability of relevant data differs across countries, particularly because of differences in how education, health care, and other systems are organized and financed. In the absence of nationally representative samples with complete cost-related data for individuals with ASDs and their families in either country, we used a bottom-up approach, drawing on previous studies, updating and supplementing them as needed, and structuring our estimates around the 7 questions listed below. A number of sources were used to estimate the costs of type of accommodation,[6,9-12] medical and nonmedical services,[7,13-17] special education,[6,18-21] employment support,[22] and productivity loss.[6,8,15,23-27] Further details of our country-specific assumptions are given in **Table 1**.

How Many People Have ASDs?

We used accepted prevalence estimates from each country. For each country, we relied on the most accepted prevalence estimates from the most reliable sources. For the United States, this source was the Centers for Disease Control and Prevention,[28] and for the United Kingdom, we relied on 3 relatively consistent prevalence studies.[10,29,30] For the United Kingdom, on the basis of population-based studies, we assumed 10% of children aged 0 to 3 years with ASDs have their condition diagnosed and receive some type of service in response (0.1% of all children in this age group), and 1.1% of children of all other ages.[7,13] For the United States, we assumed 1.1% of children and adults had ASDs and were treated.[8,28] In both cases, people in prison and defense establishments were excluded.

What Are the Characteristics and Needs of People With ASDs That Have Potential Economic Cost Implications?

Individuals with ASDs can differ greatly in their clinical and functional presentation, resulting in potentially substantial differences in costs of treatment, care, and support. The presence of ID in individuals with ASDs can greatly affect these costs. Studies[10,13,29,30] report that 40% to 60% of people with ASDs also have ID.

Costs also may vary by age. We distinguished age groups that matched administrative distinctions and data sets in each country. For the United Kingdom, we distinguished toddlers (0-1 year of age), preschool children (2-3 years of age), primary school children (4-11 years of age), secondary school children (12-17 years of age), and adults (≥18 years of age).[6] For the United States, we distinguished preschool children (0-5 years of age), school-age children (6-17 years of age), and adults (≥18 years of age).

How Does Care Differ for Individuals Based on Age and the Presence of ID?

We sought data on services and interventions for each age group, distinguishing people with and without ID. As far as possible, we included only utilization attributable to ASDs. The most recent figures on service costs of very young children were used.[31]

In What Domains Do Individuals With ASD, Their Families, and Various Service Systems Accrue Cost?

We sought data on accommodation, medical services, nonmedical services, and out-of-pocket payments by families. Cost categories sometimes referred to slightly different services in the 2 countries because of different health care, education, and other systems. For example, in the United States, accommodation refers to residential care (intermediate care facility) costs only, whereas in the United Kingdom it includes all housing (private, supported living, residential, and hospital stay). If no data were available for a particular category in one country, we applied the most relevant cost from the other country.

How Do We Estimate the Costs of These Different Types of Care?

Medical service costs include inpatient, outpatient, emergency, physician, other health care professional, home health care, pharmacy, and out-of-pocket costs. As far as possible, only service use attributable to ASDs was included. Medical costs for other family members were not included because of lack of data.

Nonmedical service costs include special education, treatment for ASD-related needs (in the United Kingdom), child care, special programs, after-school care, day care, weekend pro-

Table 1. Assumptions Used in the UK and US Cost Calculations

Variable	UK Aggregated and Mean Costs	US Incremental Costs
Accommodation	Children: All children with ASDs in residential or foster care have ID; other children with ASDs and ID live in private households; all children with ASDs without ID live in private households[9] Adults: No adults with ASDs live in prison, mobile accommodation, night shelter, temporary accommodation, or as refugees; adults with ID and adults with ASDs and ID have similar patterns of accommodation[6,10] ASDs with ID: 48% in private households, 24% in residential care, 27% in supported accommodation, 1% in hospital ASDs without ID: 79% in private households, 16% in residential care, 5% in supported accommodation, 0% in hospital	Estimates based on residential care (intermediate care facility) costs only Children: 1% of those 0-5 years of age use residential care; 5% of those 6-17 years of age use residential care[11] Adults: 19% of those 18 years and older use residential care[11]; incremental cost estimate for residential care from the article by Latkin et al[12]
Medical services	Children and adults: 100% Are assumed to be treated Cost estimates updated using 1.11 prevalence[13]	Children and adults: 100% Are assumed to be treated Cost estimates based on article by Liptak et al[14] Children: Cost of children with ASDs and ID are twice as high as those for children without ID across all ages[7]; costs of children 6-17 years of age are 1.4 times higher than costs of children 0-5 years of age[7,16] Adults: Costs of persons 18 years and older are 1.5 times higher than costs of children 6-17 years of age[15]
Nonmedical services	Children and adults: 100% Are assumed to be recognized Cost estimates updated using 1.11 prevalence[13] Mean costs assumed to vary among individuals and with age[17]	Children and adults: 100% Are assumed to be recognized Cost estimates based on article by Liptak et al[14] Children: Costs of children with ASDs and ID are twice as high as for children without ID across all ages[7]; costs of children 6-17 years of age are 1.4 times higher than costs of children 0-5 years of age[7,15] Adults: Costs of persons 18 years and older are 1.5 times higher than costs of children 6-17 years of age[15]
Special education	Children (6-17 years of age): All children in schools up to 17 years of age (note: children in special schools are usually educated up to 19 years of age)[18] Adults (≥18 years of age): Up-rated from estimates in the article by Knapp et al[6]	Children: Costs for children 0-5 years of age[19]; costs for individuals 6-21 years of age[20,21] (note: children in special schools are usually educated up to 22 years of age) Adults: Cost for those 21 years and older assumed to be zero
Employment support	Children: (0-5 and 6-17 years of age): Cost assumed to be zero Adults: Costs applied to 1.1% prevalence[13]	Children (0-5 and 6-17 years of age): Cost assumed to be zero Adults: Cost estimates based on article by Cone[22]
Parental/caregiver productivity loss/time	Children: Parents of children 0-17 years of age with ASDs and ID or without ID assumed to work 7 hours per week less than parents of children without ASDs[15] Adults (≥18 years of age): Costs based on article by Knapp et al[6] Family out-of-pocket expenses were estimated by pooling evidence from previous studies[8]	Children: Annual productivity loss for children 0-5 and 6-17 years of age with ASDs assumed to be $18 000 per year[23-25] Family out-of-pocket expenses[6,24]
Lost employment, individual	Adults: 15% of adults with ASDs without ID estimated to be in full-time employment; no adults with ASDs and ID are in open employment[6,26]; there are no data on part-time employment of individuals with ASDs and ID	Adults: 60% Unemployment rate, in other words, 40% assumed to be either full time or part time[27]; there are no data on part-time employment or employment of individuals with ASDs and ID

Abbreviations: ASD, autism spectrum disorder; ID, intellectual disability.

grams, summer school, overnight and other respite, travel to medical appointments, home care modifications, and damage replacement. Family out-of-pocket expenses were estimated by pooling evidence from previous studies,[6,8] in which further details are given.

Place of accommodation can be an important cost driver in the United Kingdom. Accommodation settings in the United Kingdom were categorized into 4 types based on previous research on people with IDs[10] (**Box**). Nonaccommodation service data for the United Kingdom came from previous studies of people with IDs.[6] Unit costs were attached to service use attributable to ASDs and largely taken from the Personal Social Services Research Unit compendium[32] adjusted to 2010-2011 prices using the Health and Community Health Services index. Figures for England were assumed to apply proportionately to Scotland, Wales, and Northern Ireland.

To estimate costs in the United States, we gathered information from a range of sources. Each cost component

Box. Accommodation Categories for Adults With Autism Spectrum Disorders (ASDs) and Intellectual Disability in the United Kingdom

We distinguished 4 accommodation categories and assumed that the distribution of adults in these categories was the same as for all adults with intellectual disabilities (ie, not just with ASDs) as estimated by Emerson and Baines[10]:

Private households: These are aggregated from the following of Emerson and Baines' categories: owner occupier or shared ownership scheme, settled mainstream housing with family and friends (including flat sharing), staying with family or friends as a short-term guest, and 50% of tenants living in living accommodation or housing association.

Residential care: These are aggregated from registered care homes and nursing homes.

Supported living accommodation: These are aggregated from adult placement scheme; sheltered housing, extra care housing, or other sheltered housing; supported accommodation, lodgings, or group home; and 50% of tenants living in living accommodation or housing association.

Hospital: These are aggregated from short-term or long-stay health care (residential) or hospital.

was extracted from the source literature and assumptions made regarding how to use these data. The main source was a comprehensive review of the peer-reviewed literature, combined with other sources for information on costs of care for individuals with ASDs in the United States.[7,8] Our approach required estimating costs for several components by functional status (presence of ID) and age groups. Because there are no data about how each cost component varies by functional status and age group, we adopted an expenditure multiples approach in which we made assumptions about relative costs as a function of an individual's age and functional status (Table 1). Mean incremental costs extracted from the literature were assumed to be overall mean incremental costs for children 0 to 17 years of age. To calculate costs for other age groups and for individuals with and without ID, we applied the multipliers presented in Table 1. To compare UK and US costs, figures in pounds sterling were converted to 2012 US dollars using the purchasing power parity rate of £0.681 for $1.[33]

What Are the Effects of Raising an Individual With ASD on Caregivers' Employment Patterns and the Associated Costs?

To our knowledge, no robust research on lost employment or productivity for parents and family members has been conducted in the United Kingdom. One US study[25] indicates that parents of a child younger than 18 years with ASD work 7 hours per week less than parents with children without ASD. We applied this US estimate to the United Kingdom. For older children, we used estimates of productivity losses from earlier research.[6] Productivity losses for adults with ASDs were based on studies of employment patterns (Table 1). Because of a lack of evidence on part-time and full-time employment of individuals with ASDs without ID, our assumptions are likely to underestimate total economic activity of noninstitutionalized adults with ASDs without ID.[13]

Opportunity costs were calculated for lost productivity as a result of lost or disrupted employment for individuals with ASDs and their families. The UK costs were calculated from national estimates of the mean national productivity rate of $21.43 per hour (£14.60 per hour),[34] resulting in estimates of annual opportunity costs of $32 007 (£21 797) and $37 656 (£25 644) for an adult with an ASD without or with ID, respectively.[6] For the United States, productivity loss was estimated to be $18 720 for caregivers of children and $1896 for caregivers of adults. Productivity loss for adults with ASDs was estimated to be $10 718.

What Is the Expected Lifespan of Individuals With ASDs?

We assumed a life expectancy of 67 years.[35] Lifetime costs for an individual with an ASD were derived by multiplying the mean cost for each age group by the number of years lived in that age group, taking a nationally weighted mean of possible accommodation experiences discounted back to present values (discount rate, 3.5%[36]).

Results

The numbers of people with ASDs are estimated to be 604 824 in the United Kingdom and 3 540 909 in the United States. Age-specific prevalence and mean annual aggregate costs by age group and presence of ID are presented in **Table 2**.

Children

Assuming a prevalence of ID of 40% among individuals with ASDs, aggregated national costs of supporting children with ASDs are £3.1 billion (US $4.5 billion) per year in the United Kingdom (excluding Social Security and benefit payments, which are transfer payments and not real societal costs) and $61 billion per year in the United States. Assuming instead a prevalence of ID of 60%, then total costs are £3.4 billion (US $5 billion) per year in the United Kingdom and $66 billion per year in the United States. Mean annual costs for a child with ID were considerably higher than those for individuals without ID. The largest contributors to total costs in both countries across all age groups were direct nonmedical costs, such as special education (including early intervention services), and indirect costs, such as parental productivity loss (**Table 3**). Costs were much higher in early childhood than for older children in the United States; in contrast, annual costs for children in the United Kingdom increased with age.

Adults

Assuming a 40% prevalence of ID, aggregated national costs for adults excluding benefit payments are £29 billion (US $43 billion) per year in the United Kingdom and $175 billion per year in the United States. Assuming prevalence of ID of 60%, costs are £31 billion (US $46 billion) per year in the United Kingdom and $196 billion per year in the United States. The largest con-

Table 2. Number of UK and US Children and Adults With Autism Spectrum Disorder and Mean Annual Cost per Individual

Variable	Age Range, y	No. of Individuals[a]	Mean Annual Cost, £ for UK and $ for US Costs
United Kingdom			
Individuals with intellectual disability	0-1	695	5904
	2-3	680	10 431
	4-11	24 492	35 069
	12-17	19 574	50 233
	≥18	196 489	86 981
Individuals without intellectual disability	0-1	1043	1412
	2-3	1020	6815
	4-17	29 361	29 767
	≥18	294 734	49 804
United States			
Individuals with intellectual disability	0-5	115 909	107 863
	6-17	227 727	85 690
	≥18	1 072 727	88 026
Individuals without intellectual disability	0-5	173 864	63 291
	6-17	341 591	52 205
	≥18	1 609 091	50 320

[a] On the basis of a 40:60 split between ID and no ID.

Table 3. Mean Annual Costs per Capita for Children (0-17 Years of Age) by Level of ID, Disaggregated by Cost Component

	UK Costs per Year (2011), £							US Costs per Year (2011), £			
	Children With ID by Age, y				Children Without ID by Age, y			Children With ID by Age, y		Children Without ID by Age, y	
Component	0-1	2-3	4-11	12-17	0-1	2-3	4-17	0-5	6-17	0-5	6-17
Accommodation or residential care (Medicaid funded)	0[a]	37	328	1240	0[a]	37	0[b]	1903	9516	952	4758
Respite care	0[a]	0[a]	3197	4078	0[a]	0[a]	7459	NA	NA	NA	
Special education	0[a]	2546	11 831	32 774	0[a]	2546	14 006	62 920	27 961[c]	31 460	13 980[c]
Employment support								0[a]	0[a]	0[a]	0[a]
Services											
Medical	267	665	988	1818	267	665	890	12 933	18 106	6467	9053
Nonmedical	0[b]	2256	7936	475	0[a]	2356	1561	11 387	11 387	5693	5693
Productivity loss (parents)	608	608	5314	5314	608	608	5314	18 720	18 720	18 720	18 720
Voluntary organization help	0[a]	69	107	107	0[a]	69	0[a]	NA	NA	NA	NA
Benefits	4154	4154	4524	4427	537	537	537	NA	NA	NA	NA
Total costs, £ ($) for United Kingdom and $ for United States	5029 (7385)	10 335 (15 176)	34 225 (50 256)	50 233 (73 763)	1412 (2073)	6818 (10 012)	29 767 (43 710)	107 863	85 690	63 292	52 205

Abbreviations: ID, intellectual disability, NA, not applicable.

[a] Assumed to be zero.

[b] No data available.

[c] Calculated for children 6 to 21 years of age.

tributors to total costs in both countries were accommodation (including the costs of staff employment in or attached to accommodation settings), followed by direct medical costs and individual productivity loss (**Table 4**). Medical costs were much higher for adults than for children.

Relative Contributions of Different Cost Categories

In the United Kingdom, 56% of the total cost for individuals with ASDs is accounted for by services, 42% by lost employment for the individual with an ASD, and the remaining 2% by caregiver time costs. In the United States, 79% of the total cost for the overall ASD population is accounted for by services, 12% by the productivity costs of individual with an ASD, and 9% by caregiver time costs.

Lifetime Costs

Discounted lifetime costs for someone with an ASD without ID were £0.92 million (US $1.36 million) in the United Kingdom and $1.43 million in the United States. Discounted lifetime costs for someone with an ASD and ID were £1.5 million

Table 4. Mean Annual Costs per Capita for Adults (≥18 Years of Age) by Level of ID, Disaggregated by Cost Component

	UK Costs per Year (2011), £		US Costs per Year (2011), $	
Cost Category	With ID	Without ID	With ID	Without ID
Accommodation	41 512	0[a]	36 161[b]	18 080[b]
Education	2619	3307	0[a]	0[a]
Employment support	290	0[a]	705	352
Services[c]				
Medical	5142	16 044	27 159	13 580
Nonmedical	2871	3610	11 387	5693
Productivity loss				
Individual with ASD	25 644	21 797	10 718	10 718
Parents	1477	1477	1896	1896
Family expenses	873	1712	0[a]	0[a]
Benefits	5671	0	0[a]	0[a]
Total costs, £ ($) for United Kingdom and $ for United States	86 099 (126 430)	47 947 (70 406)	88 026	50 319

Abbreviations: ASD, autism spectrum disorder; ID, intellectual disability.

[a] No data available.

[b] Assumed to be zero.

[c] In the United Kingdom, medical services are not separate from residential care. Adults with ID frequently are in government-sponsored residential care, the costs of which include medical care costs. Adults without ID are served in the community and therefore have higher observed medical care costs.

(US $2.20 million) in the United Kingdom and $2.44 million in the United States.

Discussion

This study presents the most comprehensive estimates to date of the financial costs of ASDs in the United States and the United Kingdom. These costs are much higher than previously suggested.[5,6] Much of the high cost associated with ASDs is due to the cost of special education in childhood and to costs associated with residential accommodation, medical care, and productivity losses in adulthood. Our findings are consistent with previous studies[6-8,37,38] that found that costs are higher for individuals with ID than without ID and that these costs persist throughout life.

The similarity in total costs between the United States and the United Kingdom is remarkable given that the 2 countries have different approaches to health care provision and financing, different emphases within the education system, and different organizational structures for residential accommodation. The 2 countries also have different data collection mechanisms within similar systems. For example, billing systems in the United States generate comprehensive, generally accurate data on health care contacts, whereas the UK National Health Service with universal free care at points of access generates much less detailed information.[39] Despite these system-level differences, similarity in the estimates suggests substitution and cost shifting among different systems to address the needs of individuals with ASDs.

A number of study limitations should be mentioned. First, we compiled estimates from a range of sources. Estimates of some costs were not available in the extant literature, so some estimates were partly reliant on expert judgment. For example, few data are available on US adults, and studies of individual and parental productivity losses are rare. There were also few reliable estimates of differences in costs for individuals who have ASDs but not ID. We also likely underestimated family costs for young adults with ASDs who have left high school but who have low rates of employment or participation in higher education.[40]

Second, although we sought to estimate costs using only robust evidence from well-conducted studies or relevant administrative sources, our cost estimates are only as good as the studies from which we extracted data. Space constraints preclude detailed discussion of the quality of each study, but we endeavored not to rely on weak sources for our estimates.

Third, there is some controversy about current ASD prevalence. The prevalence estimates we used are lower than new figures from Peacock et al[7] or Kim et al[41] (1.5% and 2.6%, respectively). Although this does not affect our per-person costs, it can markedly affect the estimated total societal costs. We rejected the estimate of Peacock et al because it is based on health care claims data with no verification of the diagnosis. We rejected the estimate of Kim et al because it is based on data from South Korea and may not be applicable to the United Kingdom or the United States.

Fourth, it was not always possible to separate costs associated with ASDs from those associated with other health conditions or impairments. This problem is common for studies that aim to estimate the overall effect (economic or otherwise) of a disease or disorder.

Fifth, in cases in which current evidence is absent or less precise than we would have wished (eg, estimates of the proportion of people with ASDs who also have ID are imprecise), we calculated overall costs on the basis of more than one assumption, and we emphasize the need to appreciate the uncertainty of our overall cost estimates.

Sixth, we have not attempted to calculate the potentially sizable nonmonetary, largely intangible (psychological) costs associated with a lifetime condition as disabling as ASDs.

Despite these limitations, there are important implications related to our new estimates. Studies of the overall economic effect of ASDs cannot form the basis for recommendations about *how* to prevent or meet needs, provide treatments, or respond to individuals' preferences. Nevertheless, by high-

lighting the scale of economic effect, the relative scale of different cost contributors, and patterns throughout life, such studies can stimulate and support policy and practice discussion.

For example, our study's findings regarding the high costs of ASDs in adulthood may help focus the attention of decision makers on the need for interventions specifically for adults or for greater attention to interventions earlier in life that have the potential to reduce later high expenditures by changing the trajectory of the disorder or the needs associated with it.[42] Similarly, the high costs associated with employment disruption for families could be addressed through workplace policies and better organization and availability of family supports, such as respite.[20,43] Another example is the high cost of residential accommodation. This high cost often is due to the high staffing levels required in some settings, raising at least 2 questions. First, are such highly staffed environments needed by all people with ASDs who currently reside there? Second, could even relatively expensive interventions that keep adults with ASDs in their communities be cost-effective?[44,45] Generally, the high and wide-ranging economic effects of ASDs should energize a search for actions that make better use of available resources.

Another clear implication of our findings is that costs span many different sectors: health, education, social care, housing, employment, welfare benefits, and labor markets. Individuals' needs are not neatly arrayed within individual systems or sectors, implying a need for effective coordination across agencies and professionals.[46,47] The high economic burden carried by families is particularly concerning; studies of costs to the health care and education systems from providing care to individuals with ASDs should be weighed against these largely unstudied family costs, which also should be compared with those of families with a member with a different (or without any) chronic condition.

Conclusions

This study gives an updated indication of the overall economic effect of ASDs in the United Kingdom and the United States. There is clearly a need for a comprehensive picture of the total economic and societal costs of ASDs in both countries (and indeed elsewhere). There also is an urgent need for a better understanding of the effectiveness and cost-effectiveness of interventions and support arrangements that address the needs and respond to the preferences of individuals with ASDs and their families. Because the economic effects of ASDs in individuals with or without ID are considerable throughout life, so too should the search for more efficient and equitable use of resources span all age groups.

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REFERENCES

1. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. 5th ed. Arlington, VA: American Psychiatric Association; 2013.

2. Taylor B, Jick H, Maclaughlin D. Prevalence and incidence rates of autism in the UK: time trend from 2004-2010 in children aged 8 years. *BMJ Open*. 2013;3(10):e003219.

3. Perou R, Bitsko RH, Blumberg SJ, et al; Centers for Disease Control and Prevention (CDC). Mental health surveillance among children: United States, 2005-2011. *MMWR Surveill Summ*. 2013;62(suppl 2):1-35.

4. Newschaffer CJ, Croen LA, Daniels J, et al. The epidemiology of autism spectrum disorders. *Annu Rev Public Health*. 2007;28:235-258.

5. Ganz M. The costs of autism. In: Moldin S, Rubenstein J, eds. *Understanding Autism: From Basic Neuroscience to Treatment*. Boca Raton, FL: CRC Press; 2006.

6. Knapp M, Romeo R, Beecham J. Economic cost of autism in the UK. *Autism*. 2009;13(3):317-336.

7. Peacock G, Amendah D, Ouyang L, Grosse SD. Autism spectrum disorders and health care expenditures: the effects of co-occurring conditions. *J Dev Behav Pediatr*. 2012;33(1):2-8.

8. Amendah D, Grosse S, Peacock G, Mandell D. The economic costs of autism: a review. In: Amaral D, Dawson G, Geschwind D, eds. *Autism Spectrum Disorders*. New York, NY: Oxford University Press; 2011.

9. Department for Education. *Children in Need (CIN): Disabled Children and Service Use*. London, England: Department for Education; 2005.

10. Emerson E, Baines S. *The Estimated Prevalence of Autism Among Adults With Learning Disabilities in England*. Lancaster, England: Learning Disabilities Observatory; 2010.

11. Birenbaum A. *In the Shadow of Medicine: Remaking the Division of Labor in Health Care*. New York, NY: General Hall; 1990.

12. Lakin K, Doljanac R, Byun SY, Stancliffe RJ, Taub S, Chiri G. Factors associated with expenditures for Medicaid home and community based services (HCBS) and intermediate care facilities for persons with mental retardation (ICF/MR) services for persons with intellectual disabilities. *Intellect Dev Disabil*. 2008;46:200-214.

13. Brugha T, Cooper SA, Kiani R, et al. *Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey*. London, England: The Health and Social Care Information Centre; 2012.

14. Liptak GS, Stuart T, Auinger P. Health care utilization and expenditures for children with autism: data from U.S. national samples. *J Autism Dev Disord*. 2006;36(7):871-879.

15. Cidav Z, Marcus SC, Mandell DS. Age-related variation in health service use and associated expenditures among children with autism. *J Autism Dev Disord*. 2013;43(4):924-931.

16. Croen LA, Najjar DV, Ray GT, Lotspeich L, Bernal P. A comparison of health care utilization and costs of children with and without autism spectrum disorders in a large group-model health plan. *Pediatrics*. 2006;118(4):e1203-e1211.

17. Synergies Economic Consulting. *Economic Costs of Autism Spectrum Disorder in Australia*. Brisbane, Australia: Synergies Economic Consulting; 2011:1-144.

18. Department for Education. *Children With Special Educational Needs 2011: An Analysis*. London, England: Department for Education; 2011.

19. Jacobson J, Mulick J, Green G. Cost-benefit estimates for early intensive behavioral intervention for young children with autism—general model and single state case. *Behav Interv*. 1998;13:201-226.

20. Chambers J, Shkolnik J, Perez M. *Total Expenditures for Students With Disabilities, 1999-2000: Spending Variation by Disability.* Washington, DC: American Institutes for Research in the Behavioral Sciences, United States Department of Education, Office of Special Education Programs; 2003.

21. Chambers J, Parrish T, Harr J. *What Are We Spending on Special Education Services in the United States, 1999-2000?* Washington, DC: American Institutes for Research in the Behavioral Sciences, United States Department of Education, Office of Special Education Programs; 2004.

22. Cone AA. *Fact Sheet: Supported Employment.* Richmond: Virginia Commonwealth University Rehabilitation Research and Training Center on Supported Employment; 2008.

23. Järbrink K. The economic consequences of autistic spectrum disorder among children in a Swedish municipality. *Autism*. 2007;11(5):453-463.

24. Järbrink K, Fombonne E, Knapp M. Measuring the parental, service and cost impacts of children with autistic spectrum disorder: a pilot study. *J Autism Dev Disord*. 2003;33(4):395-402.

25. Cidav Z, Marcus SC, Mandell DS. Implications of childhood autism for parental employment and earnings. *Pediatrics*. 2012;129(4):617-623.

26. National Autistic Society. *Autism and Asperger Syndrome: Some Facts and Statistics.* London, England: National Autistic Society; 2012.

27. Howlin P, Alcock J, Burkin C. An 8 year follow-up of a specialist supported employment service for high-ability adults with autism or Asperger syndrome. *Autism*. 2005;9(5):533-549.

28. Centers for Disease Control and Prevention. *Prevalence of Autism Spectrum Disorders: Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008.* Atlanta, GA: Centers for Disease Control and Prevention; 2012.

29. Baron-Cohen S, Scott FJ, Allison C, et al. Prevalence of autism-spectrum conditions: UK school-based population study. *Br J Psychiatry*. 2009;194(6):500-509.

30. Fombonne E. Epidemiological surveys of autism and other pervasive developmental disorders: an update. *J Autism Dev Disord*. 2003;33(4):365-382.

31. Barrett B, Byford S, Sharac J, et al; PACT Consortium. Service and wider societal costs of very young children with autism in the UK. *J Autism Dev Disord*. 2012;42(5):797-804.

32. Curtis L. *Unit Cost of Health and Social Care 2011.* Canterbury, England: Personal Social Services Research Unit, University of Kent; 2011.

33. Organisation for Economic Cooperation and Development. PPPs and exchange rates. Published 2012. http://stats.oecd.org/Index.aspx?datasetcode=SNA_TABLE4. Accessed December 5, 2012.

34. Office of National Statistics. *Annual Survey of Hours and Earnings.* London, England: Office of National Statistics; 2011.

35. Shavelle RM, Strauss D. Comparative mortality of persons with autism in California, 1980-1996. *J Insur Med*. 1998;30(4):220-225.

36. Treasury HM. *The Green Book: Appraisal and Evaluation in Central Government.* London, England: Stationery Office; 2004.

37. Ganz ML. The lifetime distribution of the incremental societal costs of autism. *Arch Pediatr Adolesc Med*. 2007;161(4):343-349.

38. Kogan MD, Strickland BB, Blumberg SJ, Singh GK, Perrin JM, van Dyck PC. A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005-2006. *Pediatrics*. 2008;122(6):e1149-e1158.

39. Ham C. Money can't buy you satisfaction. *BMJ*. 2005;330(7491):597-599.

40. Roux AM, Shattuck PT, Cooper BP, Anderson KA, Wagner M, Narendorf SC. Postsecondary employment experiences among young adults with an autism spectrum disorder. *J Am Acad Child Adolesc Psychiatry*. 2013;52(9):931-939.

41. Kim YS, Leventhal BL, Koh YJ, et al. Prevalence of autism spectrum disorders in a total population sample. *Am J Psychiatry*. 2011;168(9):904-912.

42. Peters-Scheffer N, Didden R, Korzilius H, Matson J. Cost comparison of early intensive behavioral intervention and treatment as usual for children with autism spectrum disorder in the Netherlands. *Res Dev Disabil*. 2012;33(6):1763-1772.

43. Mandell DS, Xie M, Morales KH, Lawer L, McCarthy M, Marcus SC. The interplay of outpatient services and psychiatric hospitalization among Medicaid-enrolled children with autism spectrum disorders. *Arch Pediatr Adolesc Med*. 2012;166(1):68-73.

44. Mandell DS. Psychiatric hospitalization among children with autism spectrum disorders. *J Autism Dev Disord*. 2008;38(6):1059-1065.

45. Felce D, Perry J, Romeo R, et al. Outcomes and costs of community living: semi-independent living and fully staffed group homes. *Am J Ment Retard*. 2008;113(2):87-101.

46. Shattuck PT, Grosse SD. Issues related to the diagnosis and treatment of autism spectrum disorders. *Ment Retard Dev Disabil Res Rev*. 2007;13(2):129-135.

47. Hyman SL, Johnson JK. Autism and pediatric practice: toward a medical home. *J Autism Dev Disord*. 2012;42(6):1156-1164.