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.
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. The increase in the number of individuals diagnosed as having ASDs 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 and 2009 for the United Kingdom; 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. 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, medical and nonmedical services, special education, employment support, and productivity loss. 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, and for the United Kingdom, we relied on 3 relatively consistent prevalence studies. For the United King-
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 (Box).

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

<table>
<thead>
<tr>
<th>Variable</th>
<th>UK Aggregated and Mean Costs</th>
<th>US Incremental Costs</th>
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| **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<sup>9</sup>  
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<sup>8,10</sup>  
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<sup>10</sup>  
Adults: 19% of those 18 years and older use residential care<sup>11</sup>; incremental cost estimate for residential care from the article by Latkin et al<sup>12</sup> |
| **Medical services** | Children and adults: 100% Are assumed to be treated  
Cost estimates updated using 1.11 prevalence<sup>13</sup> Mean costs assumed to vary among individuals and with age<sup>17</sup> | Children and adults: 100% Are assumed to be treated  
Cost estimates based on article by Liptak et al<sup>14</sup>  
Children: Cost of children with ASDs and ID are twice as high as those for children without ID across all ages<sup>2</sup>; costs of children 6-17 years of age are 1.4 times higher than costs of children 0-5 years of age<sup>7,16</sup>  
Adults: Costs of persons 18 years and older are 1.3 times higher than costs of children 6-17 years of age<sup>15</sup> |
| **Nonmedical services** | Children and adults: 100% Are assumed to be recognized  
Cost estimates updated using 1.11 prevalence<sup>13</sup> Mean costs assumed to vary among individuals and with age<sup>17</sup> | Children and adults: 100% Are assumed to be recognized  
Cost estimates based on article by Liptak et al<sup>14</sup>  
Children: Costs of children with ASDs and ID are twice as high as those for children without ID across all ages<sup>2</sup>; costs of children 6-17 years of age are 1.4 times higher than costs of children 0-5 years of age<sup>7,16</sup>  
Adults: Costs of persons 18 years and older are 1.3 times higher than costs of children 6-17 years of age<sup>15</sup> |
| **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)<sup>18</sup>  
Adults (≥18 years of age): Up-rated from estimates in the article by Knapp et al<sup>6</sup> | Children: Costs for children 0-5 years of age<sup>19</sup>; costs for individuals 6-21 years of age<sup>20,21</sup> (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<sup>13</sup> | Children (0-5 and 6-17 years of age): Cost assumed to be zero  
Adults: Cost estimates based on article by Cone<sup>22</sup> |
| **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<sup>13</sup>  
Adults (≥18 years of age): Costs based on article by Knapp et al<sup>6</sup>  
Family out-of-pocket expenses were estimated by pooling evidence from previous studies<sup>6</sup> | Children: Annual productivity loss for children 0-5 and 6-17 years of age with ASDs assumed to be $18 000 per year<sup>23-25</sup>  
Family out-of-pocket expenses<sup>5-24</sup> |
| **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<sup>6,26</sup>; 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<sup>27</sup>; there are no data on part-time employment or employment of individuals with ASDs and ID |

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

**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. 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 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. 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.

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), resulting in estimates of annual opportunity costs of $32 007 (£21 797) and $77 656 (£52 644) for an adult with an ASD without or with ID, respectively. 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.

### 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-
Contributors 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.
Research Original Investigation

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. 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 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 healthcare 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. 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.

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 or Kim et al (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-

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

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

<table>
<thead>
<tr>
<th>Cost Category</th>
<th>UK Costs per Year (2011), £</th>
<th>US Costs per Year (2011), $</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accommodation</td>
<td>With ID 4512</td>
<td>Without ID 0</td>
</tr>
<tr>
<td>Education</td>
<td>2619</td>
<td>3307</td>
</tr>
<tr>
<td>Employment support</td>
<td>290</td>
<td>0</td>
</tr>
<tr>
<td>Services</td>
<td>Medical 5142</td>
<td>16 044</td>
</tr>
<tr>
<td>Nonmedical</td>
<td>2871</td>
<td>3610</td>
</tr>
<tr>
<td>Productivity loss</td>
<td>Individual with ASD 25 644</td>
<td>21 797</td>
</tr>
<tr>
<td>Parents</td>
<td>1477</td>
<td>1477</td>
</tr>
<tr>
<td>Family expenses</td>
<td>873</td>
<td>1712</td>
</tr>
<tr>
<td>Benefits</td>
<td>5671</td>
<td>0</td>
</tr>
<tr>
<td>Total costs, £ ($) for United Kingdom and $ for United States</td>
<td>86 099 (126 430)</td>
<td>47 947 (70 406)</td>
</tr>
</tbody>
</table>

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

a No data available.

b Assumed to be zero.

* 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.
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. 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? 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. 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.


