

Lifetime costs for autism spectrum disorder may reach \$2.4 million per patient

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This is the Director of the Center for Mental Health Policy and Services Research and associate professor of Psychiatry and Pediatrics at Penn. Credit: Penn Medicine

Costs for a lifetime of support for each individual with autism spectrum disorder may reach \$2.4 million, according to a new study from researchers from the Perelman School of Medicine at the University of Pennsylvania and the Children's Hospital of Philadelphia. In a study published online today in *JAMA Pediatrics*, the team found that costs for a person with ASD and an intellectual disability reaches \$2.4 million in the United States and \$2.2 million in the United Kingdom; costs for those who have ASD without an intellectual disability are estimated to cost \$1.4 million in both the U.S. and the U.K.

Autism spectrum disorder is a neurodevelopmental condition that leads



to significant social, communication and behavioral challenges. It commonly co-occurs with <u>intellectual disability</u>, a cognitive impairment that begins in childhood and causes below-average intellectual function and a lack of skills necessary for daily living.

ASDs can be a major source of stress on the long-term health, and social and financial well-being on affected individuals, their families and society as a whole.

"We sought to look at the overall economic affect of ASDs, not just the cost of caring for this population, but also the costs of individual and parental <u>productivity loss</u> across both the U.S. and the U.K.," says senior author David Mandell, ScD, Director of the Center for Mental Health Policy and Services Research and associate professor of Psychiatry and Pediatrics at Penn. "We also separated out those with intellectual disabilities (ID), as the presence of ID may significantly influence costs."

The team, which included investigators from Penn and the London School of Economics, analyzed existing literature in both countries, updating and supplementing as needed to estimate the cost of accommodation, medical and non-medical services, special education, employment support and productivity loss. Differences in how education, health care and other systems are organized and financed between the two countries made this somewhat of a challenge.

The number of people with ASD is estimated at 3,540,909 in the U.S. and 604,824 in the U.K. Assuming 40 percent of those with ASD also have an ID, the aggregate national cost of supporting children with ASD was estimated at \$61 billion per year in the US, and \$4.5 billion per year in the UK. When the number of patients with ID was estimated to be 60 percent, costs climbed to \$66 billion per year in the US and \$5 billion per year in the UK.



Assuming a 40 percent prevalence of ID, the aggregate costs for adults was \$175 billion per year in the US and \$43 billion in the UK; these numbers grew to \$196 billion and \$46 billion, respectively, when the proportion of adults with ID was increased to 60 percent.

For ASD individuals without ID, the lifetime cost was estimated at \$1.43 million in the U.S. and \$1.36 million in the U.K.

The largest contributor to total costs in both countries across all age groups were direct nonmedical costs, such as <u>special education</u> in childhood and <u>indirect costs</u>, such as parental productivity loss and productivity losses in adulthood since most of these individuals may encounter difficulty working.

"These numbers provide important information that can help policy makers and advocacy organizations make decisions about how to allocate resources to best serve this population," says Mandell. "Of particular importance is that one of the largest <u>costs</u> was parents' lost wages. This finding makes it imperative that we examine how high-quality intervention can reduce burden on families, allowing them to stay in the work force. It also suggests the need for policies that make the work place more friendly to families of children with disabilities."

More information: Paper: *JAMA Pediatr*. Published online June 9, 2014. DOI: 10.1001/jamapediatrics.2014.210
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