

Annual cost of autism has more than tripled - \$126 billion US and £34 billion in the UK

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Autism Speaks, the world's leading autism science and advocacy organization, today announced preliminary results of new research that estimates autism costs society a staggering \$126 billion per year (U.S.) – a number that has more than tripled since 2006, and annually in the U.K. has reached more than £34 billion (equivalent to \$54 billion U.S.). The costs of providing care for each person with autism affected by intellectual disability through his or her lifespan are \$2.3 million in the U.S. and £1.5 million (\$2.4 million) in the U.K. The lifetime costs of caring for individuals who are not impacted by intellectual disability are \$1.4 million in the U.S. and £917,000 in the U.K. (equivalent to \$1.46 million). The Autism Speaks-funded research, conducted by researchers Martin Knapp, Ph.D., of the London School of Economics, and David Mandell, Sc.D., of the University of Pennsylvania, will be presented at the international conference "Investing in our Future: The Economic Costs of Autism," hosted by Goldman Sachs in collaboration with the Child Development Centre and Autism Speaks, on March 31 in Hong Kong.

Drs. Knapp and Mandell compiled information from recent studies of autism <u>costs</u> from multiple sources to calculate the current cost of autism associated with the current CDC-reported prevalence that 1:110 children are diagnosed with an autism spectrum disorder (ASD). The cost of autism continues to grow with the rise in prevalence. While the latest prevalence estimates in the U.S. and U.K. are comparable, the primary difference in total costs of autism in the U.S. and U.K. are due to differences in total country population (five times larger in the U.S. than



the U.K.). The research team found that the cost of autism in the U.S. alone is greater than the entire Gross Domestic Product (GDP) of 139 countries around the world.

Bob Wright, co-founder of Autism Speaks, said, "Autism is a global public health crisis. The costs are staggering and will continue to rise as prevalence continues to increase. We know that early diagnosis and treatment are critical, so it is imperative that the U.S. and governments around the world step up their commitment to helping people living with autism today. The investment we make now is essential to reducing the long-term costs of autism."

This research found that <u>intellectual disability</u> plays a major role in the cost of autism to individuals, families, and society as a whole. The costs of autism per year are nearly twice as high on average for children and adults with intellectual disability than for children and adults without intellectual disability, \$2.3 million in the U.S. and £1.5 million in the U.K. (\$2.4 million) for those individuals who are impacted by intellectual disability compared with more than \$1.4 million in the U.S. and £917,000 (\$1.46 million) in the U.K. for those who do not have intellectual disability.

A number of factors were considered by the researchers that contributed to the cost differential between U.S. and U.K. lifetime and total costs. The education and healthcare systems in the two countries offer different responses to the needs of people with autism and their families. Access to empirical data regarding healthcare and education costs differed between the two countries. It is also currently estimated that 45 percent of individuals with ASD in the U.S. and 55 percent of individuals with ASD in the U.K. have intellectual disabilities, defined as an IQ of 70 or less. Experts consistently point to early interventions as key to increasing language and IQ scores, and reducing life span costs.



Total costs to the U.S. were also based on adult prevalence of one-half of one percent, lower than currently estimated 1:110 prevalence of autism in children, derived from past CDC studies. The researchers point to adult prevalence as an area for additional study in the U.S.

The research also found that non-medical costs account for the greatest proportion of expenses. While direct medical costs, such as outpatient care, home care, and pharmacy, contribute significantly to overall expenses, non-medical costs, including intervention services and special education, child daycare, and especially residential placements and care for adults who age out of school and can no longer live at home with parents account for the largest proportion of autism costs.

"The burden on families affected by autism is enormous," continued Autism Speaks President Mark Roithmayr. "The extraordinary cost further exacerbates that burden. The time and effort involved in coordinating the care and treatment plan across a large number of providers has reduced the ability of many families to earn a living. Too many families are still denied insurance coverage for essential treatments and services, and the economics add to overall emotional burden on families."

Building on this preliminary research, Autism Speaks recently provided additional funding to Drs. Knapp and Mandell to support an additional year of study to examine how autism therapies reduce lifetime costs associated with autism. Their investigation will focus on both intensive preschool behavioral interventions and vocational interventions that support an individual's independence during the transition to adulthood. Calculations will take into account costs related to healthcare, education, caregiving, housing, and employment.

As confirmed by this study, the majority of costs related to autism are incurred during adulthood, principally due to the cost of residential care



as well as loss of productivity, underemployment and unemployment among adults with autism. Services for adults are both lacking and expensive.

In 2007, Michael L. Ganz, Ph.D. of the Harvard School of Public Health published research in the journal *Archives of Pediatric and Adolescent Medicine* which estimated that autism cost the United States more than \$35 billion per year, and that the incremental cost of caring for an individual with autism over his or her lifetime due to their special needs was more than \$3 million. Despite growing prevalence, autism currently receives less than five percent of the research funding of many less prevalent childhood diseases and disorders.

Dr. Mandell added, "We are paying for the costs of inaction and the costs of 'inappropriate action.' Social exclusion of individuals with autism and intellectual disability, and exclusion of higher-functioning individuals from employment opportunities are increasing the burden not only on these individuals and their families, but on society as a whole."

Dr. Mandell and his colleagues recently published findings in *Pediatrics* that mothers of children with ASD are less likely to work, work fewer hours per week and earn substantially less. Typically the primary caregiver, mothers are called upon to serve as their child's case manager and advocate, and on average, earn 56 percent less than mothers of children with no health limitations. They earn 35 percent less than mothers of children with another health limitation. They are 6 percent less likely to be employed, and they work an average of seven hours less per week.

Dr. Knapp, Professor of Social Policy at the London School of Economics and Political Science and a preeminent expert on health economics explained that the economic burden of <u>autism</u> varies widely across different parts of society from the individuals with ASD, their



families, the communities they live in, businesses in those communities, to the government agencies which provide healthcare, education, welfare benefits, social care, and housing. "There is an immediate need for better coordination across public agencies and levels of government from local to national in the way that society structures its service delivery system; too often responses to the needs of individuals and families are piecemeal and less helpful than they could be," he concluded.

Provided by Autism Speaks

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