

Interagency Autism Coordinating Committee Budget Recommendation

Autism spectrum disorder (ASD) is a lifelong condition, and as such, it results in significant human costs across the lifespan, not only in healthcare and services costs, but also in lost economic productivity, and reduced individual quality of life. These true costs reflecting lost human potential have recently begun to be described by thorough analyses. One of the most notable studies to date has estimated that the total lifetime cost (including spending and lost productivity) for supporting a person with ASD in the United States averages \$2.4 million for ASD with intellectual disability, and \$1.4 million for ASD without intellectual disability [1]. Another study estimated that the additional costs of healthcare, education, therapy, services, and caregiver time associated with caring for a child with ASD aged 3 to 17 years is about \$17,000 per year [2].

The total annual cost of ASD in the United States – including medical, non-medical, economic, and lifetime costs, among others – has been estimated to be at least \$236 billion. Of the estimated \$236 billion, the cost of supporting children with ASD was at least \$61 billion per year, and the annual cost for adults with ASD was at least \$175 billion [1]. Another study has suggested that in 2015 the combined medical, non-medical, and lost productivity costs were in the range of \$162-\$367 billion, or 0.89-2.0% of the U.S. gross domestic product [3]. By contrast, the Interagency Autism Coordinating Committee (IACC) portfolio analysis data from 2015 indicates that the combined autism research funding among federal and private sources totaled \$343 million – a mere 0.09-0.21% of the estimated total annual cost of ASD.

While it is evident that more work needs to be done to fully understand the impacts of ASD on our society, there are several ways in which investment in research may be able to effect long-term benefits to individuals and society, as well as cost savings. Research on the biological basis of ASD may lead to the identification of modifiable risk factors that could reduce disability associated with ASD, as well as enable earlier diagnosis and improved interventions. There is already evidence that the costs of research and services that enable delivery of effective early intensive behavioral interventions in childhood can result in cost savings over the lifespan by reducing the need for costly long-term care and support [4, 5]. In addition, we know that an estimated four out of ten young adults with autism do not transition to a job within the first years after completing high school, and those who do find work are often relegated to part-time or low-wage jobs [6]. It is therefore also likely that more investment in research to improve adolescent and adult services and supports would improve the economic productivity of individuals over their entire lifetime, while also improving their sense of purpose and quality of life [7].

Although there was significant growth in autism research funding from 2008 to 2010, and additional federal funding from the American Recovery and Reinvestment Act provided a welcome boost in 2009-2010, ASD research funding levels have since become relatively flat. The loss in momentum has been accelerated by the loss of purchasing power over time due to inflation, resulting in what was effectively 15% of funding that was lost to inflation in 2015 alone (Figure X). At the same time, never before has there been such promising scientific advances in ASD research, as well as a recognition of the full range of ASD research that will require attention and resources in order to truly improve the lives of individuals across the autism spectrum and lifespan. In the *2016-2017 IACC Strategic Plan*, the IACC has identified 22 new strategic objectives that represent areas of significant opportunity in the autism field that with enhanced funding have the potential to address critical needs of the autism community. Particularly as more and more adolescents with ASD reach adulthood, it will be important to increase investment in the research that enables the development and delivery of evidence-based practices to better serve this population.

With these goals in mind, the IACC considered historical ASD funding trends and projected the budgets that will be necessary to propel ASD research and ensure meaningful progress on the priorities identified in this newly updated *IACC Strategic Plan*.

[Insert language about budget recommendations, once method is determined.]

References:

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