2021-2023 IACC Strategic Plan for Autism Research, Services, and Policy Draft January 2023

Budget Recommendation

In the preceding chapters, the Interagency Autism Coordinating Committee (IACC) has provided information about recent research progress and services activities as well as strategic Objectives to guide future efforts to better understand and address the needs of people on the autism spectrum across the lifespan and all levels of ability and disability. Under the Autism CARES Act, the IACC is also required to include "proposed budgetary requirements" in the Strategic Plan. The following information provides the IACC budget recommendation and supporting background information for the 2021-2023 Strategic Plan for Autism Research, Services, and Policy.

The IACC Calls for \$685 Million in Annual Autism Research Funding by 2025

To spur significant growth in autism research, the 2016-2017 IACC Strategic Plan called for a doubling of the 2015 autism research budget to \$685 million by 2020. To accomplish this goal, the IACC recommended a nearly 15% annual increase in autism research funding across combined federal and private funders. The Committee recognized that this was an ambitious goal, but it believed that such an increase could have great impact if achieved. As reported in the 2019-2020 Portfolio Analysis Report, autism research funding in 2020 totaled \$409.2 million (see Figure 1). While this did not meet the 2016-2017 IACC Strategic Plan recommendation, autism research did experience a substantial growth in funding from when the original 2016-2017 budget recommendation was made, increasing by 12% since 2016.

To update the budget recommendation included in the current *Strategic Plan*, the IACC now calls for the autism research budget to reach \$685 million by 2025. This is in recognition of the fact that funding did not reach \$685 million by 2020 as originally called for in 2016. Furthermore, although there was significant growth in autism research funding from 2008 to 2010, and additional federal funding from the American Recovery and Reinvestment Act (ARRA) provided a welcome boost in 2009 and 2010, autism 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 (Figure 2).

The Committee considered historical autism funding trends and projected budgets and decided to extend this target amount of \$685 million to 2025. With steady and predictable annual increases, this would require approximately a \$55.2 million annual increase in autism research funding combined across federal and private funders. The Committee believes that this is a realistic and attainable goal for enhanced research funding to address the critical needs of the autism community. In addition, future funding will continue to grow with increasing awareness of ways to support people on the spectrum and the involvement of new organizations joining in support of autism research efforts. New private funders will play an important role in the expansion of autism research, as non-federal organizations may have the ability to use creative funding mechanisms and support work in areas that have not been historically covered. If met, this budget recommendation will help to propel autism research forward and ensure that there is meaningful progress on the priorities identified in this *Strategic Plan*. These funds should be used to support the full range of autism research that will require attention and resources in order to truly improve the lives of people on the spectrum and their families.

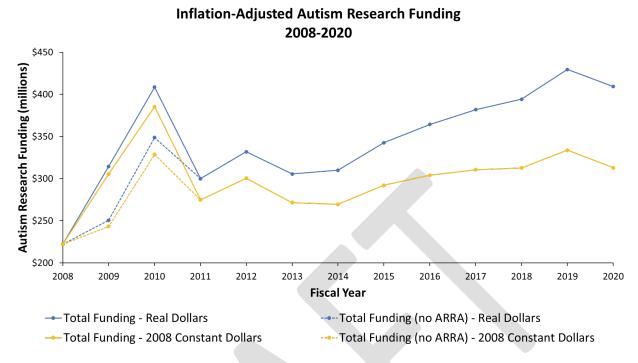


Figure 2. The history of combined federal and private autism research funding from 2008 to 2020 in actual (blue) dollars and 2008 constant (orange) dollars. The dotted lines indicate funding levels excluding American Recovery and Reinvestment Act (ARRA) stimulus funds, which provided supplementary funding in 2009 and 2010. Inflation effects were calculated using the Biomedical Research and Development Price Index (BRDPI).¹

It is important to point out that this budget recommendation applies to only the autism research budget; this does not include funding for important services, supports, and programs. The present budget recommendation does not take into account much of the day-to-day spending of families. The research funding described will help to provide the evidence needed to identify interventions, services, and supports that are effective and that work for individuals with a variety of needs and co-occurring conditions across the lifespan. It is also important to note that the research funding increases recommended by the IACC would not be sufficient to accomplish all the research goals identified in this Plan.

Given the tremendous needs of the autism community as well as the promising opportunities for research and services, the committee identified three specific high-priority research areas that could greatly benefit from targeted funding increases. While all areas of the autism research portfolio require increases in funding, the areas identified by the IACC that are in particular need of resource growth include:

¹ National Institutes of Health (NIH) Office of Budget. "GDP Table of Annual and Cumulative Values for 1950 through 2027"

https://officeofbudget.od.nih.gov/pdfs/FY22/gbipricesindexes/GDP%20Table%20of%20Annual%20and%20Cumula tive%20Values%20for%201950%20through%202027.pdf

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- 1. **Lifespan issues**: Increased funding is needed in research on issues that are relevant to autistic adults, such as transition to adulthood, higher education, employment, housing, healthcare, lifelong learning, service, and support opportunities, community integration, and healthy aging.
- 2. **Evidence-based interventions and services**: Increasing the evidence base for new and existing interventions and services will provide additional guidance to autistic individuals and their families as they seek solutions to maximize positive outcomes.
- 3. Research on disparities and development of culturally competent tools and services: Continued investment is needed to close the existing gaps in outcome measures due to differences across race/ethnicity/culture, sex/gender, sexual orientation, geographic location, and socioeconomic status.

The sections above highlight three high-priority research areas that are in particular need of resources and attention. An infusion of resources would be wisely and efficiently leveraged in these areas, as research progress to date demonstrates that researchers in these fields are well-poised to capitalize on additional investment. Moreover, the targeted allocation of resources to these areas would serve not only to incentivize research on these topics but also to expand the diversity of the workforce and encourage additional well-trained scientists to specialize in these research areas of significant need. With expanded resources and a diversified workforce that includes those with lived experience, the full range of autism research will have the potential to make significant advancements in the coming years and truly impact the lives of individuals across the autism spectrum and lifespan.