Overview of Progress on Strategic Plan Objectives

The *IACC Strategic Plan* provides a framework to guide the autism research efforts of federal and private funders. The *Plan* organizes research priorities around seven general topic areas represented as community-focused "Questions." The Questions are divided further into research Objectives that address key research needs, gaps, and opportunities identified by the Committee. For the current *Plan*, the IACC made several updates and language changes to the Objectives to reflect the voices and current needs of the autism community. The organization of the general topic area Questions remained unchanged, which enables evaluation of research progress in these areas over the last thirteen years. A complete evaluation of these research areas over time is provided in the *2019-2020 IACC Autism Research Portfolio Analysis Report*.

In 2020, autism research funding supported projects relevant to all seven Questions in the *2016-2017 IACC Strategic Plan for ASD Research*. In addition, all of the *Strategic Plan* Objectives were supported by funded projects. This indicates that the priority areas identified by the IACC were deemed by federal and private research funders to be worthy of investment. However, some areas received greater proportions of funding than others due to the activities of the funders included in the analysis. As in previous years, Question 2 (Biology) received the largest portion of funding (45%) in 2020. Research in this field focuses on identifying the biological differences and mechanisms in early development and throughout life that contribute to autism, as well as the characterization of the behavioral and cognitive aspects of autism. Projects ranged from basic neuroscience using cellular and animal models to human/clinical studies. Question 3, research which aimed at identifying genetic and environmental factors that may contribute to autism, had the second largest portion of funding (18%). Question 3 research projects addressed topics such as identifying genetic mutations commonly found in individuals on the autism spectrum, developing improved approaches to studying environmental exposures and gene-environment interactions, and exploring the potential roles of the microbiome and epigenetics in autism. Investment in research infrastructure and prevalence (Question 7) and services and supports (Question 5) both had a significant proportion of funding at 9%. Projects in Question 7 covered data sharing, research workforce development, epidemiological studies on autism prevalence, and communication/dissemination of research findings and evidence-based practices. Question 5 projects addressed issues surrounding access to services; coordination of community-based supports; assessment of health and safety; and improving efficacy, cost-effectiveness, and implementation of evidence-based practices. Interventions (Question 4) followed with 8% of total funding, which included research on behavioral therapies, pharmacological/medication-based approaches, and technology-based interventions, including assistive communication technologies and computer and artificial intelligence-based skill training. Research projects in Question 4 encompass the development of new interventions using model systems and small-scale experiments as well as full-scale clinical trials. Research to improve screening and diagnosis (Question 1) of autism was 7% of funding in 2020. Question 1 Objectives focused on research to develop biomarkers, screening tools, and diagnostic instruments to aid in early identification. Research focused on lifespan (Question 6) remained the smallest areas of funding (4%). Research projects within Question 6 attempted to identify and address gaps in transition to adulthood and long-term outcomes in quality of life for people on the autism

spectrum, including research on post-secondary education, employment, housing, adult healthcare, and community integration.

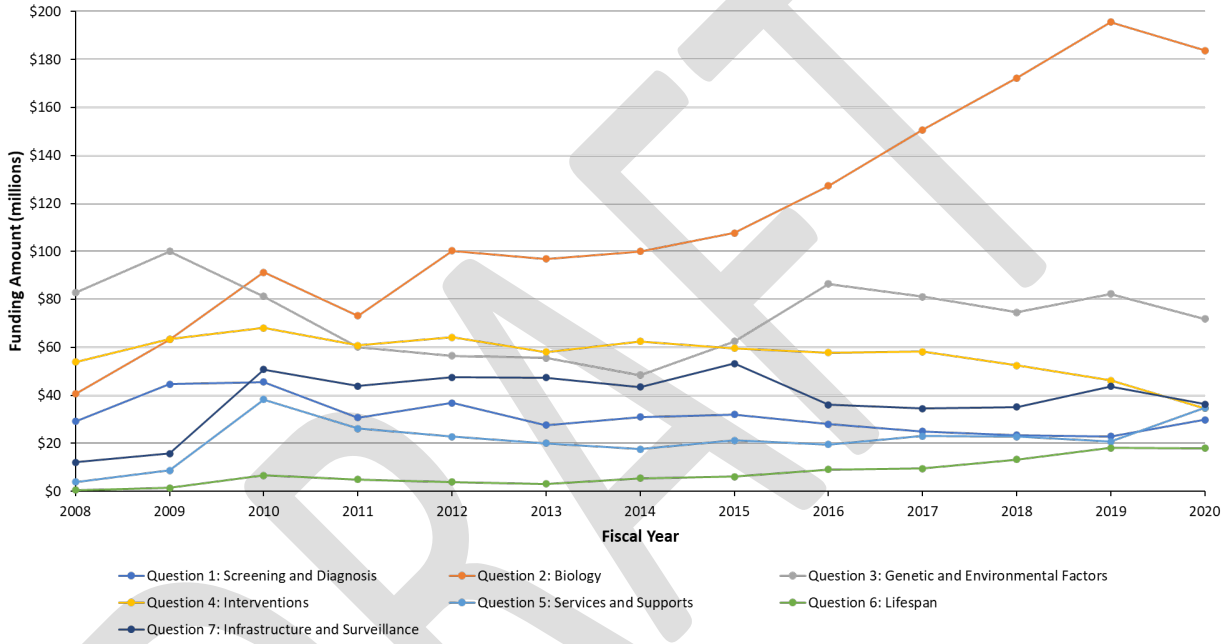

Figure X. Autism research funding from 2008 to 2020, broken down by *Strategic Plan* Question area.

Figure X shows the trend in funding for each of the Question areas over time. In 2008, the reported autism research funding for federal agencies and private organizations was $222.2 million and 745 projects. In 2020, funding for autism research among both federal and private funders totaled $409.2 million and spanned 1,536 research projects. Over the thirteen years, autism research showed a general upward trend in funding, increasing by 84% since 2008. However, not all Question areas have shown the same pattern of growth. Question 2 (Biology) is the research area that has shown by far the most dramatic increases in funding, peaking at $195.6 million in 2019. In 2020, research on genetic and environmental factors (Question 3) received the second largest amount of research dollars. Funding amounts for Question 3 started out relatively high in 2008, then dipped from 2011-2014, but have shown relative increases in recent years. Question 1 (Screening and Diagnosis), Question 5 (Services), and Question 7 (Infrastructure) have received largely consistent investments in research since 2008. Funding for Question 4 (Interventions) has also been fairly stable but has been on a slight downward

trend in recent years. Research focused on lifespan (Question 6) has consistently received the lowest levels of funding but has shown encouraging growth over the past four years.

Looking over the last thirteen years, significant advances have been made in autism research in each of the Question areas prioritized by the Committee. Since the development of the last *IACC Strategic Plan*, autism researchers have made several important discoveries and reached many milestones. However, there are still many areas of research that lack the support needed to foster significant progress. The IACC identified three specific high-priority research areas that could greatly benefit from targeted funding increases: X, Y, Z. These priority areas are described in greater detail in the Budget Recommendation section on p. X. While additional investment is particularly needed in these areas of autism research, an overall increase in funding to support the entire autism portfolio will be critical to move the field forward and capitalize on scientific opportunity. This new edition of the *IACC Strategic Plan* builds on the priorities established in the previous editions of the *Strategic Plan*, identifies gaps in research, and provides recommendations for future research and services endeavors so that we continue to make a difference in the lives of people on the autism spectrum and their families.