2019-2020 AUTISM RESEARCH
PORTFOLIO ANALYSIS REPORT

IACC
INTERAGENCY AUTISM
COORDINATING COMMITTEE

OFFICE OF
NATIONAL AUTISM
COORDINATION
NATIONAL INSTITUTES OF HEALTH

INTERAGENCY AUTISM COORDINATING COMMITTEE (IACC)

2019-2020 AUTISM RESEARCH
PORTFOLIO ANALYSIS REPORT

Cover Design

NIH Medical Arts Branch

Copyright Information

Suggested Citation

Table of Contents

About the IACC

The Interagency Autism Coordinating Committee (IACC) is a federal advisory committee charged with coordinating federal activities concerning autism spectrum disorder (ASD) and providing advice to the Secretary of Health and Human Services (HHS) on issues related to autism. The Committee was established by Congress under the Children's Health Act of 2000, reconstituted under the Combating Autism Act (CAA) of 2006, and renewed most recently under the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2019.

Membership of the Committee includes a wide array of federal agencies involved in autism research and services, as well as public stakeholders, including autistic adults, family members of those on the autism spectrum, advocates, service providers, and researchers, who represent a variety of perspectives. The IACC's diverse membership ensures the Committee is equipped to address the broad range of issues and challenges faced by individuals and families in the autism community.

Under the CAA and subsequent authorizations, the IACC is required to (1) develop and annually update a strategic plan for autism research, (2) develop and annually update a summary of advances in autism research, and (3) monitor federal activities related to autism.

Through these and other activities, the IACC provides guidance to HHS and partners with other federal departments, research and advocacy organizations, and the broader autism community to accelerate research and enhance services with the goal of positively impacting the lives of people on the autism spectrum and their families.

For more information about the IACC, see **https://iacc.hhs.gov/**.

Editorial Note on References to Autism: The IACC supports the use of accessible language around autism in its publications. The terms "person with autism," "person with ASD," "autistic person," and "person on the autism spectrum" are used interchangeably throughout this document. Some members of the autism community prefer one term, while others prefer another. The Committee respects the different opinions within the community on the use of this language and does not intend to endorse any particular preference. In addition, the term "autism" is generally used in this document, and "ASD" is used when referring specifically to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5-TR)-defined diagnosis.

Acknowledgments

The IACC Autism Research Portfolio Analysis Reports would not be possible without the cooperation and partnership of the federal departments and agencies and private organizations that support autism research. The time and efforts of all funders who contributed to the portfolio analysis are greatly appreciated by the IACC and the Office of National Autism Coordination. Contributing funders are listed below, and descriptions of their work can be found in **Appendix B**.

Federal Funders
- Department of Health and Human Services (HHS)
  - Administration for Community Living (ACL)
  - Agency for Healthcare Research and Quality (AHRQ)
  - Centers for Disease Control and Prevention (CDC)
  - Food and Drug Administration (FDA)
  - Health Resources and Services Administration (HRSA)
  - National Institutes of Health (NIH)
- Defense Advanced Research Projects Agency (DARPA)
- Department of Defense – Army (DoD – Army)
- Department of Education (ED)
- Environmental Protection Agency (EPA)
- Institute of Museum and Library Services (IMLS)
- National Endowment for the Arts (NEA)
- National Science Foundation (NSF)
- Social Security Administration (SSA)

Private Funders
- Autism Research Institute (ARI)
- Autism Science Foundation (ASF)
- Autism Speaks (AS)
- BRAIN Foundation (BRAIN)
- Brain & Behavior Research Foundation (BBRF)
- Eagles Autism Foundation (Eagles)
- Els for Autism Foundation (ELS)
- Escher Fund for Autism/Escher Family Fund (EFA)
- FRAXA Research Foundation (FRAXA)
- New England Center for Children (NECC)
- New Jersey Governor's Council for Medical Research and Treatment of Autism (NJGCA)
- Organization for Autism Research (OAR)
- Patient-Centered Outcomes Research Institute (PCORI)
- Simons Foundation (SF)
- Thrasher Research Fund (Thrasher)
- Tuberous Sclerosis Alliance (TSCA)

INTRODUCTION AND ANALYSIS FRAMEWORK

The Office of National Autism Coordination (ONAC) at the National Institute of Mental Health (NIMH), National Institutes of Health (NIH) supports the activities of the IACC. The first **IACC Autism Research Portfolio Analysis Report** was issued in 2008 to provide the Committee with comprehensive information about the status of autism research funding among federal agencies and private research organizations in the United States.

The *2008 Portfolio Analysis Report*, along with extensive input from federal and public stakeholders, informed the development of the first **IACC Strategic Plan for Autism Spectrum Disorder Research** that was published in 2009. The Strategic Plan provides a framework to guide the efforts of federal and private funders of autism research. The IACC Portfolio Analysis Reports align autism research projects with Objectives described in the IACC Strategic Plan. The reports present funding for research projects related to Strategic Plan Objectives and track funding over time. The IACC has used this information in their efforts to monitor autism research and determine progress made each year toward accomplishing the Objectives in the IACC Strategic Plan.

The **2016-2017 IACC Strategic Plan for Autism Spectrum Disorder**, which was the most recent edition of the Strategic Plan when this report was prepared, organizes research priorities around seven general topic areas represented as community-focused "Questions." Each Strategic Plan Question includes three to four primary Objectives, and there is one Cross-Cutting Objective on autism in women and girls. This *2019-2020 IACC Autism Research Portfolio Analysis Report* presents trends in autism research funding from 2008 to 2020 and alignment of research projects with the primary Objectives of the *2016-2017 IACC Strategic Plan*, as well as the Cross-Cutting Objective. An analysis of funding for projects that align with the Cross-Cutting Theme on disparities in autism, introduced in the **2017-2018 Portfolio Analysis Report**, is also included.

To ensure that the portfolio analysis represents the most comprehensive view of the U.S. autism research landscape, ONAC and the IACC regularly review available information about autism research to identify additional funders to partner in this effort. In 2019 and 2020, five federal funders and four private funders, each of which is supporting autism biomedical and services research, were added to the portfolio analysis. This ensures that the Portfolio Analysis Report provides as accurate an estimate as possible of total autism research funding in the United States.

Accompanying the *2019-2020 IACC Autism Research Portfolio Analysis Report* is detailed federal and private funder project data, available in the Autism Research Database (ARD) and accessible via the IACC website (**https://iacc.hhs.gov/funding/data/**). This database provides the autism community and other members of the public with a centralized place from which to gather valuable information about autism research that can support their efforts to serve the autism community. See **Appendix E** for additional information about the ARD.

The IACC Strategic Plan Questions and Corresponding Research Areas

ONAC requested information on 2019 and 2020 autism research projects funded by federal agencies and private organizations, including the annual funding amount and the relevance of each project to the seven critical Questions of the *2016-2017 IACC Strategic Plan*. The seven IACC Strategic Plan Questions are also represented by corresponding research areas, illustrated below (**Figure 1**).

QUESTION 1: How can I recognize the signs of autism, and why is early detection so important?

SCREENING & DIAGNOSIS

1 Strengthen the evidence base for the benefits of early detection of autism.
2 Reduce disparities in early detection and access to services.
3 Improve/validate existing or develop new tools, methods, and service delivery models for detecting autism in order to facilitate timely linkage of individuals on the autism spectrum to early, targeted interventions and supports.

QUESTION 2: What is the biology underlying autism?

BIOLOGY

1 Foster research to better understand the processes of early development, molecular and neurodevelopmental mechanisms, and brain circuitry that contribute to the structural and functional basis of autism.
2 Support research to understand the underlying biology of co-occurring conditions in autism and to understand the relationship of these conditions to autism.
3 Support large-scale longitudinal studies that can answer questions about the development of autism from pregnancy through adulthood and the natural history of autism across the lifespan.

QUESTION 3: What causes autism, and can the disabling aspects of autism be prevented or preempted?

GENETIC & ENVIRONMENTAL FACTORS

1 Strengthen understanding of genetic factors for autism across the full diversity and heterogeneity of those with autism, enabling development of strategies for reducing disability and co-occurring conditions in autism.
2 Understand the effects on autism of individual and multiple exposures in early development, enabling development of strategies for reducing disability and co-occurring conditions in autism.
3 Expand knowledge about how multiple environmental and genetic factors interact through specific biological mechanisms to manifest in autism phenotypes.

QUESTION 4: What treatments and interventions will help?

INTERVENTIONS

1 Develop and improve pharmacological and medical interventions to address both core symptoms and co-occurring conditions in autism.
2 Create and improve psychosocial, developmental, and naturalistic interventions for the core symptoms and co-occurring conditions in autism.
3 Maximize the potential for technologies and development of technology-based interventions to improve the lives of people on the autism spectrum.

QUESTION 5: What kinds of services and supports are needed to maximize quality of life for people on the autism spectrum?

SERVICES & SUPPORTS

1 Scale up and implement evidence-based interventions in community settings.
2 Reduce disparities in access and in outcomes for underserved populations.
3 Improve service models to ensure consistency of care across many domains with the goal of maximizing outcomes and improving the value that individuals get from services.

QUESTION 6: How can we meet the needs of people on the autism spectrum as they progress into and through adulthood?

LIFESPAN

1 Support development and coordination of integrated services to help youth make a successful transition to adulthood and provide supports throughout the lifespan.
2 Support research and implement approaches to reduce disabling co-occurring physical and mental health conditions in adults on the autism spectrum, with the goal of improving safety, reducing premature mortality, and enhancing quality of life.
3 Support research, services activities, and outreach efforts that facilitate and incorporate acceptance, accommodation, inclusion, independence, and integration of people on the autism spectrum into society.

QUESTION 7: How do we continue to build, expand, and enhance the infrastructure system to meet the needs of the autism community?

INFRASTRUCTURE & PREVALENCE

1 Promote growth, integration, and coordination of the biorepository infrastructure.
2 Develop, enhance, and link data repositories.
3 Expand and enhance the research and services workforce, and accelerate the pipeline from research to practice.
4 Strengthen autism surveillance systems to further understanding of the population of individuals on the autism spectrum, while allowing comparisons and linkages across systems as much as possible.

CROSS-CUTTING OBJECTIVES

The Cross-Cutting Objective and Theme focus on specific themes that occur across all Question areas. The goal of creating a unified Cross-Cutting Objective/Theme is to encompass the numerous research and services priorities identified by the Committee throughout the Strategic Plan and to highlight these areas as a priority for funders.

1 Support research to understand the underlying biology of sex differences in autism, possible factors that may be contributing to underdiagnosis, unique challenges that may be faced by girls/women on the autism spectrum, and develop strategies for meeting the needs of this population.
2 Support advances in research and improvements in services access and delivery that reduce disparities for underrepresented and underserved populations.

Figure 1. The seven Questions, corresponding research areas, and the 23 Objectives of the *2016-2017 IACC Strategic Plan*, including the Cross-Cutting Objective on autism in women and girls, as well as the Cross-Cutting Theme on disparities in autism.

Subcategory Classification

In 2010, the Subcategory classification system (**Figure 2**) was introduced to the IACC Portfolio Analysis Reports. The application of Subcategory coding to projects helps to divide the portfolio into easy-to-understand topical areas, such as "Cognitive Studies," "Family Well-Being and Safety," and "Data Tools." This breakdown helps the Committee and other readers of the report understand the types of research encompassed by the projects in the research portfolio. For the Subcategory analysis, each project was assigned to a Question and then a Subcategory based on the research area it addresses.

IACC STRATEGIC PLAN RESEARCH AREAS BY SUBCATEGORY

A Subcategory classification system was created to allow an understanding of the autism research portfolio based on simple research topics that are relevant to each of the IACC Strategic Plan Questions. Appendix C provides detailed definitions of the Subcategory research areas.

SCREENING & DIAGNOSIS

- Diagnostic and Screening Tools
- Early Signs and Biomarkers
- Phenotypes/Subgroups
- Spectrum of Characteristics

BIOLOGY

- Cognitive Studies
- Computational Science
- Co-Occurring Conditions
- Developmental Trajectory
- Immune/Metabolic Pathways
- Molecular Pathways
- Neural Systems
- Neuropathology
- Sensory and Motor Function
- Subgroups/Biosignatures

GENETIC & ENVIRONMENTAL FACTORS

- Environmental Factors
- Epigenetics
- Gene-Environment
- Genetic Factors

INTERVENTIONS

- Behavioral
- Complementary, Dietary, and Alternative
- Educational
- Medical/Pharmacologic
- Model Systems/ Therapeutic Targets
- Occupational, Physical, and Sensory-Based
- Technology-Based

SERVICES & SUPPORTS

- Community Inclusion Programs
- Efficacious and Cost-Effective Service Delivery
- Family Well-being and Safety
- Practitioner Training
- Services Utilization and Access

LIFESPAN

- Community Integration Supports and Services
- Daily Life Skills
- Health and Behavioral Outcomes
- Health Care Systems/ Health Care Transition
- Transition to Adulthood and Postsecondary Outcomes

INFRASTRUCTURE & PREVALENCE

- Biobanks
- Data Tools
- Prevalence Studies
- Research Infrastructure
- Research Recruitment and Clinical Care
- Research Workforce Development

Figure 2. The Subcategory classification system used to code projects in the Portfolio Analysis Report. This allows for an understanding of the autism research portfolio based on simple research topics that are relevant to each of the IACC Strategic Plan Questions. **Appendix C** provides detailed definitions of the Subcategory research areas for each Question.

AUTISM RESEARCH FUNDERS AND FUNDING IN 2019 AND 2020

Who funded autism research in 2019 and 2020?

Fourteen federal departments and agencies and 16 private organizations contributed their autism research funding information for the *2019-2020 Autism Research Portfolio Analysis Report*. These 30 funders are listed in **Table 1**.[1] The IACC and ONAC routinely review the funding landscape and offer opportunities for additional funders to join the IACC portfolio analysis effort. This regular review enables the report to provide a depiction that is as comprehensive as possible of federal and private contributions to autism research in the United States. Additionally, new funders often expand the scope of autism research and fill in gaps in the field. For the present report, five federal funders and four private organizations were identified and added to the analysis. These additions are the **Defense Advanced Research Projects Agency (DARPA)**, the **Food and Drug Administration (FDA)**, the **Institute of Museum and Library Services (IMLS)**, the **National Endowment for the Arts (NEA)**, the **Social Security Administration (SSA)**, the **BRAIN Foundation**, the **Eagles Autism Foundation**, the **Els for Autism Foundation**, and the **Thrasher Research Fund**. Added funders accounted for 0.5% ($2.3 million) and 1.2% ($4.9 million) of total funding in 2019 and 2020, respectively. The research projects that are added by these funders are important in understanding the autism research landscape but did not alter the overall funding trajectory observed in the portfolio. Some agencies and organizations included in previous years' analyses did not have projects to report in 2019 or 2020 or chose not to participate in the present analysis. Brief summaries of the mission areas of each agency and organization that contributed to the *2019-2020 Portfolio Analysis Report* can be found in **Appendix B**.

FEDERAL	PRIVATE
- Administration for Community Living (ACL) - Agency for Healthcare Research and Quality (AHRQ) - Centers for Disease Control and Prevention (CDC) - Defense Advanced Research Projects Agency (DARPA)* - Department of Defense – Army (DoD-Army) - Department of Education (ED) - Environmental Protection Agency (EPA) - Food and Drug Administration (FDA)* - Health Resources and Services Administration (HRSA) - Institute of Museum and Library Services (IMLS)* - National Endowment for the Arts (NEA)* - National Institutes of Health (NIH) - National Science Foundation (NSF) - Social Security Administration (SSA)* * Funders newly added to the Portfolio Analysis Report in 2019 and 2020	- Autism Research Institute (ARI) - Autism Science Foundation (ASF) - Autism Speaks (AS) - BRAIN Foundation (BRAIN)* - Brain & Behavior Research Foundation (BBRF) - Eagles Autism Foundation (Eagles)* - Els for Autism Foundation (ELS)* - Escher Fund for Autism/Escher Family Fund (EFA) - FRAXA Research Foundation (FRAXA) - New England Center for Children (NECC) - New Jersey Governor's Council for Medical Research and Treatment of Autism (NJGCA) - Organization for Autism Research (OAR) - Patient-Centered Outcomes Research Institute (PCORI) - Simons Foundation (SF) - Thrasher Research Fund (Thrasher)* - Tuberous Sclerosis Alliance (TSCA)

Table 1. Projects from 14 federal agencies and 16 private organizations were included in the *2019-2020 IACC Autism Research Portfolio Analysis Report*.

---

1   Within the portfolios of funders who focus on rare genetic disorders with strong links to autism (e.g., the Tuberous Sclerosis Alliance), only projects that are directly related to autism were included in the present report analyses.

How much autism research was funded in 2019 and 2020?

Combined, the federal and private investment in autism research was $424,202,347 in 2019 and $418,915,385 in 2020. Overall funding for autism research increased by 7.6% ($30.0 million) from 2018 to 2019. From 2019 to 2020, total autism funding decreased by 1.2% ($5.3 million).

Funders newly added to the portfolio analysis accounted for 7.6% ($2.3 million) of the increase from 2018 to 2019. Not including the contributions of the seven additional funders, funding increased by 7.0% from 2018 to 2019 ($27.7 million). Without newly added funders in 2020, the decrease from 2019 to 2020 was 1.5% ($6.5 million).

The relative proportions contributed by federal and private funders during 2019 and 2020 remained similar from year to year. In 2019, the federal government provided $349.9 million (903 projects) in autism research funding and accounted for 82.5% of overall funding. Private organizations provided $74.3 million (701 projects) in funding, which accounted for 17.5% of the total funding in 2019 (**Figure 3**). In 2020, the federal government provided $345.8 million (891 projects) in autism research funding and accounted for 82.6% of overall funding. Private organizations provided $73.1 million (682 projects), which accounted for 17.4% of the total funding in 2020 (**Figure 4**). This breakdown of federal and private funding is consistent with what has been observed in previous years: 83% federal, 17% private in 2018; 81% federal, 19% private in 2017; and 80% federal, 20% private in 2016.

2019
Federal vs. Private Funding for Autism Research
Total Funding: $424,202,347
Number of Projects: 1,604

Private
17.5%
$74,326,593
701 projects

Federal
82.5%
$349,875,753
903 projects

Figure 3. In 2019, 82.5% of autism research funding was provided by federal sources, while 17.5% of funding was provided by private organizations.

2020
Federal vs. Private Funding for Autism Research
Total Funding: $418,915,385
Number of Projects: 1,573

Private
17.4%
$73,073,062
682 projects

Federal
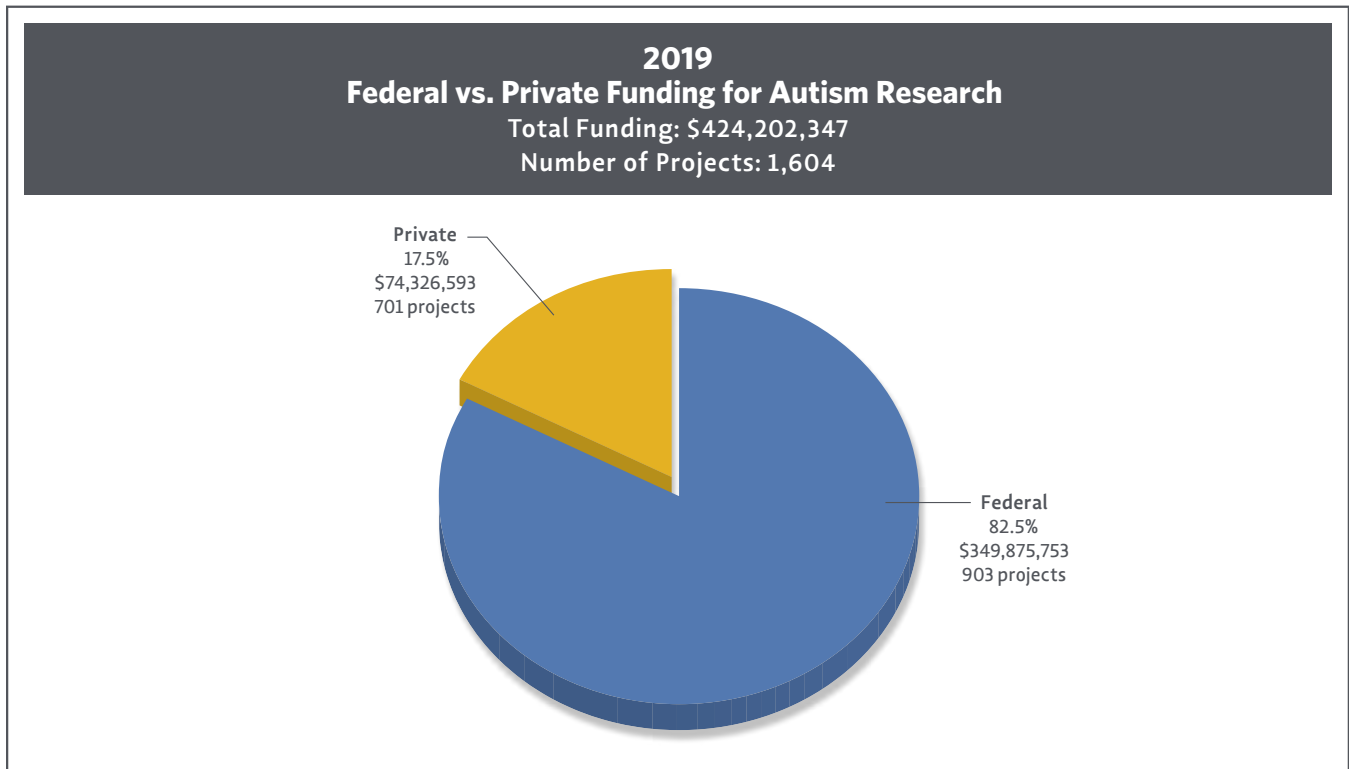82.6%
$345,842,322
891 projects
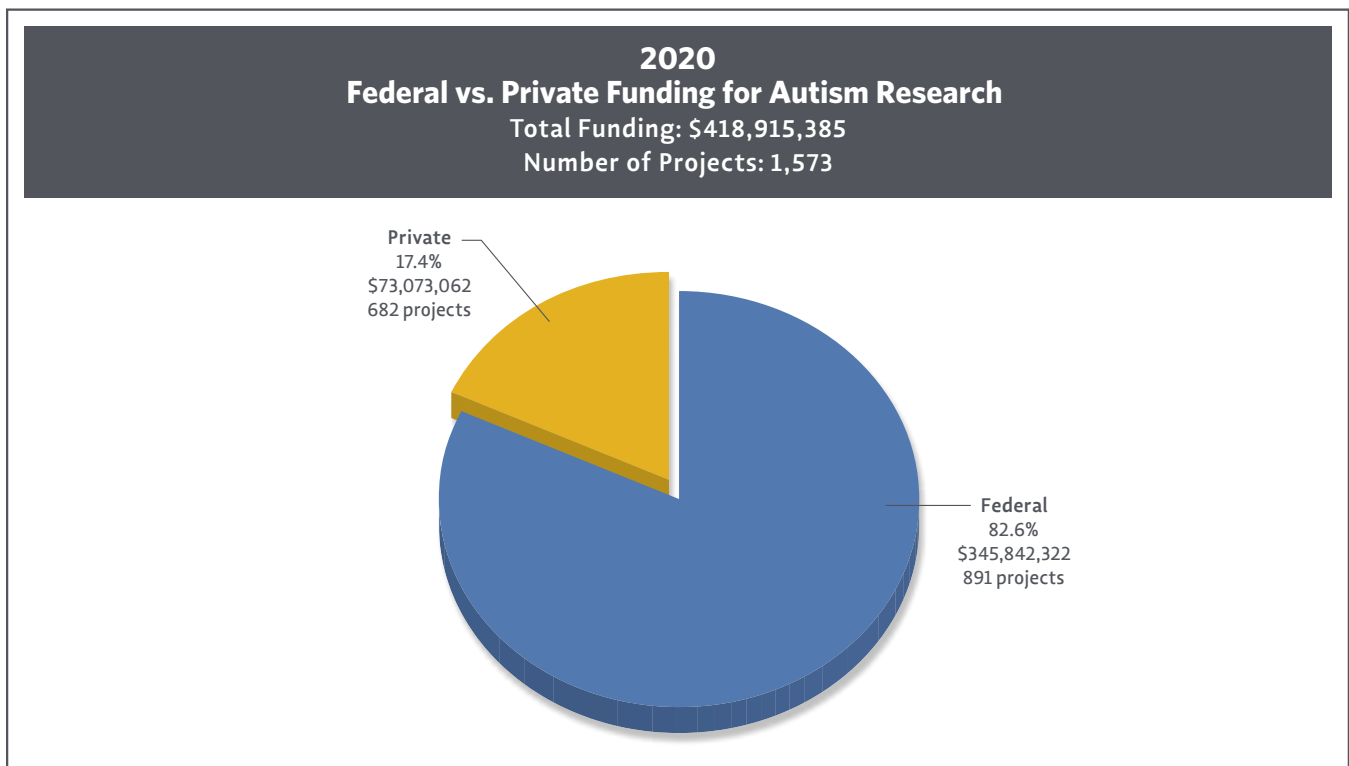
Figure 4. In 2020, 82.6% of autism research funding was provided by federal sources, while 17.4% of funding was provided by private organizations.

How many new autism research projects were added in 2019 and 2020 compared to ongoing research?

To evaluate trends in funding directed towards the continuation of ongoing research versus newly initiated projects, the status of each project included in the portfolio analysis is classified as either "Ongoing" or "New." Ongoing projects were active in a previous year, and new projects became active and received funding for the first time in the specified year of analysis. Since most research projects are funded over multiple years, a larger number of ongoing projects compared to new

projects is expected. In 2019, 70.0% ($297.1 million) of overall autism research funding went to ongoing projects while 30.0% ($127.1 million) went to new projects. In 2020, 74.4% ($311.7 million) of total autism funding was assigned to ongoing projects while 25.6% ($107.2 million) were new projects. This breakdown is similar to historical trends, which show that ongoing projects typically account for 70-80% of total funding and new projects account for 20-30% (**Figure 5**).

Percent of Funding for New vs. Ongoing Projects 2009 - 2020

* Project status was not tracked in the *2008 IACC Portfolio Analysis Report*.
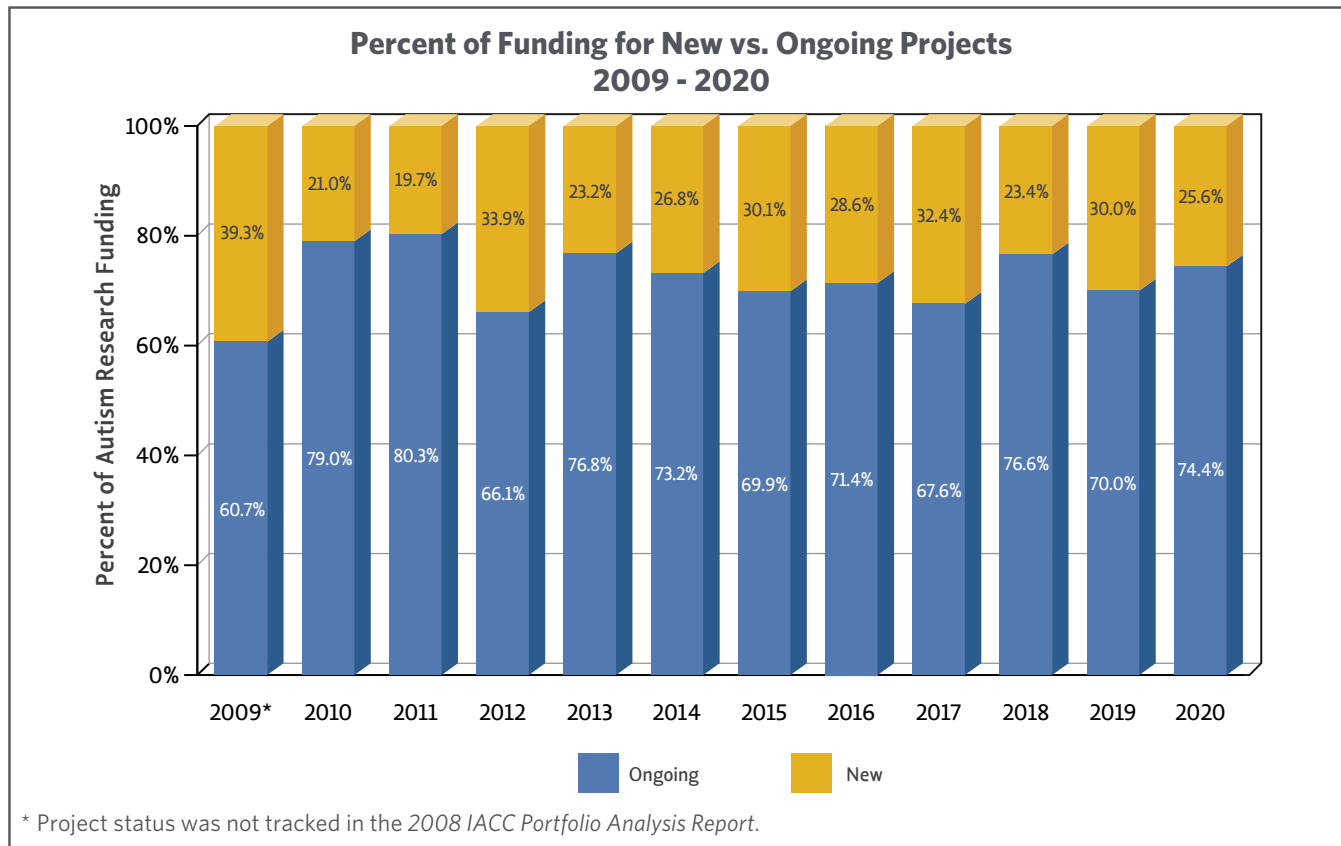
Figure 5. The percent of autism research funding from 2009 to 2020 directed to ongoing versus new projects.

Funding for new projects increased by $34.9 million (37.8%) in 2019 ($127.1 million) compared to 2018 ($92.2 million). This is at least partially due to the initiation of several large new projects funded by the National Institutes of Health, National Science

Foundation, and Department of Defense – Army. In 2020, total funding for new projects ($107.2 million) decreased by $19.9 million (15.7%) compared to 2019. However, 2020 funding for new projects was still $15.0 million (16.2%) more than 2018 funding levels.

What funding trends were observed?

- Overall, autism research funding increased from 2018 to 2020 (**Figure 6**).

  – In 2018, the combined federal and private investment in autism research was $394.2 million.

  – In 2019, the combined federal and private investment in autism research was $424.2 million, an increase of 7.6% ($30.0 million) from the previous year.

  – In 2020, the combined federal and private investment in autism research was $418.9 million, a decrease of 1.2% ($5.3 million) from 2019.

- The amount of federal investment in autism research increased by 7.0% ($23.0 million) in 2019 ($349.9 million) from 2018 ($326.9 million). It decreased by 1.2% ($4.0 million) in 2020 ($345.8 million) from 2019.

- The amount of private investment in autism research increased by 10.4% ($7.0 million) in 2019 ($74.3 million) from 2018 ($67.4 million). It decreased by 1.7% ($1.3 million) in 2020 ($73.1 million) from 2019.

- As described in previous IACC Portfolio Analysis Reports, the American Recovery and Reinvestment Act (ARRA) provided an additional $63.9 million in 2009 and $59.9 million in 2010 to support autism research projects. This created a temporary increase in total autism research funding during those years, resulting in a high of $408.6 million in 2010. In the years following, funding levels decreased in comparison to 2010. With steady increases in recent years, 2019 and 2020 autism funding levels surpassed the previous high in 2010.

- According to an analysis of the impact of inflation over time, however, autism research funding peaked in terms of purchasing power in 2010 at $385.2 million in inflation-adjusted 2008 constant dollars (**Figure 7**).
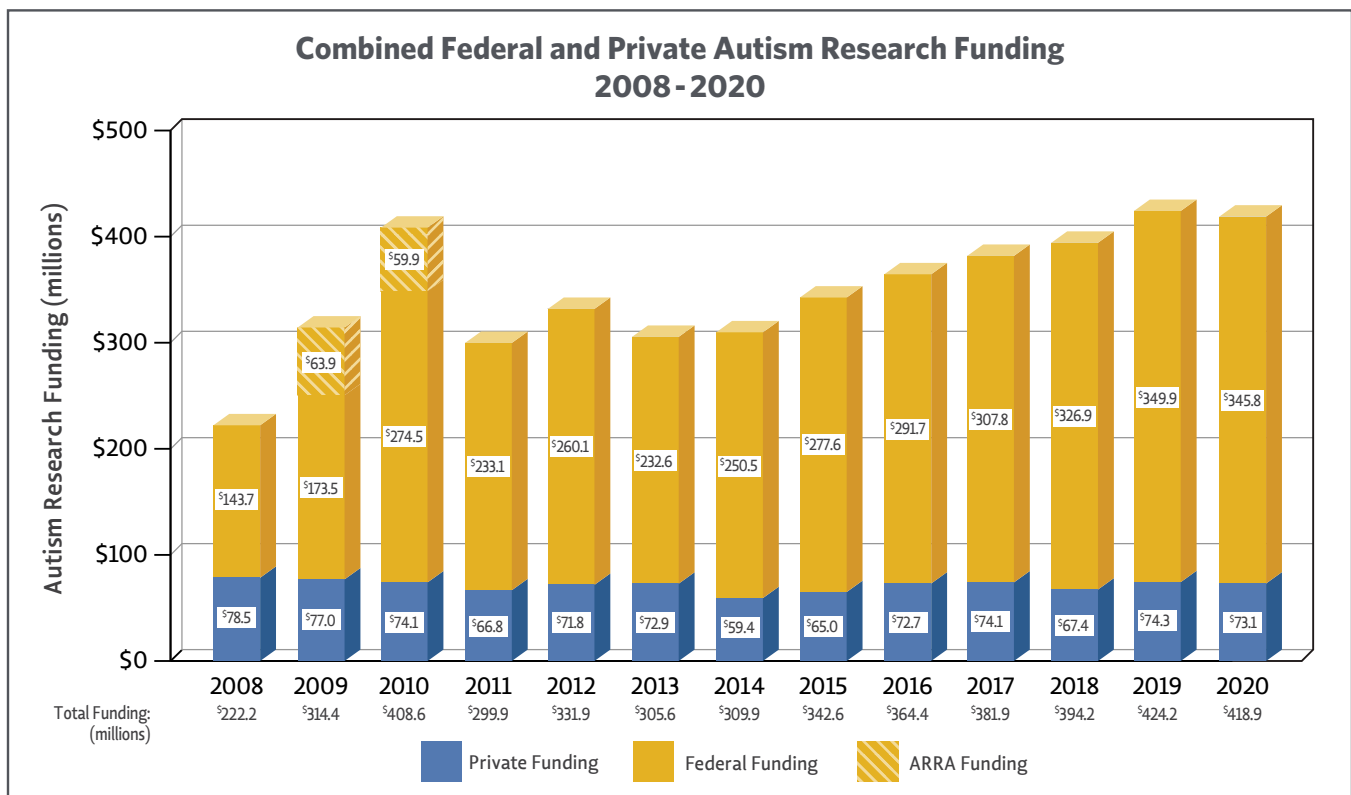
Figure 6. 2008-2020 autism research funding from federal (yellow) and private (blue) sources based on data collected for the IACC Portfolio Analysis Report of those years. Yellow dashed shading indicates supplementary funding provided by the American Recovery and Reinvestment Act (ARRA) in 2009 and 2010. Funding amounts in this figure are rounded to nearest tenth of a million. See **Table 10** in Appendix A for exact funding amounts for each year.

Inflation-Adjusted Autism Research Funding 2008-2020
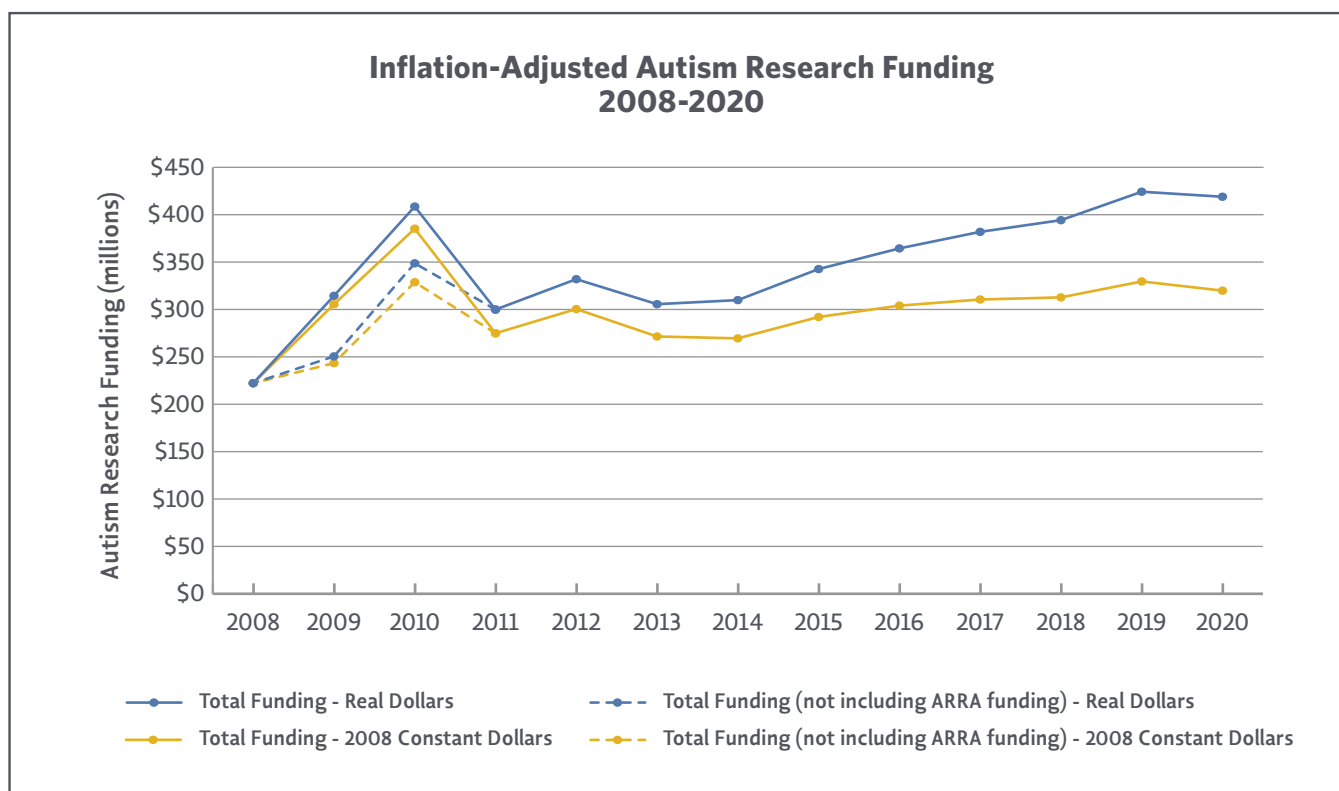
Figure 7. The history of combined federal and private autism research funding from 2008 to 2020 in actual dollars (blue) and 2008 constant dollars (yellow), based on data collected for the IACC Portfolio Analysis Report for those years. The dotted lines indicate funding levels excluding ARRA stimulus funds, which provided supplementary funding in 2009 and 2010. Inflation effects were calculated using the **Biomedical Research and Development Price Index (BRDPI)**.

From 2008 to 2020, funding increased by 88.5% ($196.7 million), demonstrating an overall trajectory of growth in support of autism research. However, funding has varied from one year to the next during that time (**Figure 6**). An infusion of funds from the ARRA in 2009 and 2010 took autism research funding to a high of $408.6 million in 2010, but funding then decreased in 2011. There was an increase in 2012, followed by decreases in 2013 and 2014. Steady growth occurred from 2015 through 2018. In 2019, the autism research portfolio was funded at its highest level ever at $424.2 million, representing a 7.6% ($30.0 million) increase from 2018. While this increase over a one-year period is not unprecedented, it was larger than the average yearly increase of 4% from 2016 to 2018. In 2020, funding levels decreased by 1.2% ($5.3 million) compared to 2019, though this was still 6.3% ($24.7 million) higher in comparison to 2018.

Contributors to Funding Trends

Over the years of portfolio analysis tracking, fluctuations in funding have been observed, which can result from factors such as the release of new initiatives and sunsetting of other initiatives, changes in organization budgets and priorities, changes in government appropriations, and the effects of using certain funding mechanisms. For example, some funders allocate all funding to a project in the first year, while others disburse the funds over regularly spaced intervals. These different disbursement mechanisms may result in fluctuation of overall funding levels from one year to another. Additionally, some funders may not have an established and consistent autism research portfolio and thus may provide one-time or sporadic funding for specific autism-related projects or initiatives.

Availability of resources for different funders, particularly those in the private sector, may also vary from year to year.

In this Portfolio Analysis Report, a decrease in funding was observed from 2019 to 2020. The above factors may have contributed. It is also important to note that the decrease in 2020 funding levels coincided with the start of the coronavirus disease 2019 (COVID-19) pandemic. Research across many scientific disciplines was affected by the pandemic, and autism research may have been similarly impacted. Monitoring of the 2021 and 2022 funding cycles in future Portfolio Analysis Reports will shed further light on variations in funding levels and the overall trajectory of growth of autism research in recent years.

Where is autism research being funded in the United States?

Figure 8 shows the distribution of autism research projects across the United States funded by both federal agencies and private organizations in 2020. The map shows that research is concentrated along the east and west coasts and in major metropolitan areas or areas with large universities in the middle portion of the country.

The U.S. institutions that received the largest amounts of funding in 2019 and 2020 are the University of California, Davis (UC Davis); Yale University; and the University of California, Los Angeles (UCLA). UC Davis has many investigators collaborating on major autism research initiatives such as the **Baby Siblings Consortium** and **SPARK**. It is also the site of the **UC Davis MIND Institute**, **UC Davis Center for Children's Environmental Health and Disease Prevention (CCEH)**, and the Center for the Development of

Phenotype-Based Treatments of Autism Spectrum Disorder. Yale University is similar in that researchers at the institution are collaborating on several large multisite research projects, such as the **Simons Simplex Collection (SSC)** and the **Autism Biomarkers Consortium for Clinical Trials (ABC-CT)**. UCLA includes researchers also involved in the **Baby Siblings Consortium**, as well as the **SSC** and the **Autism Sequencing Consortium (ASC)**, two major research initiatives investigating the genetics of autism. Many of the other institutions with large amounts of funding are involved in large genetic, biological, and environmental research networks in efforts to increase the study size and quality of the research being conducted. **Tables 2** and **3** provide additional information about the institutions and states that received the largest amounts of autism research funding in 2019 and 2020.
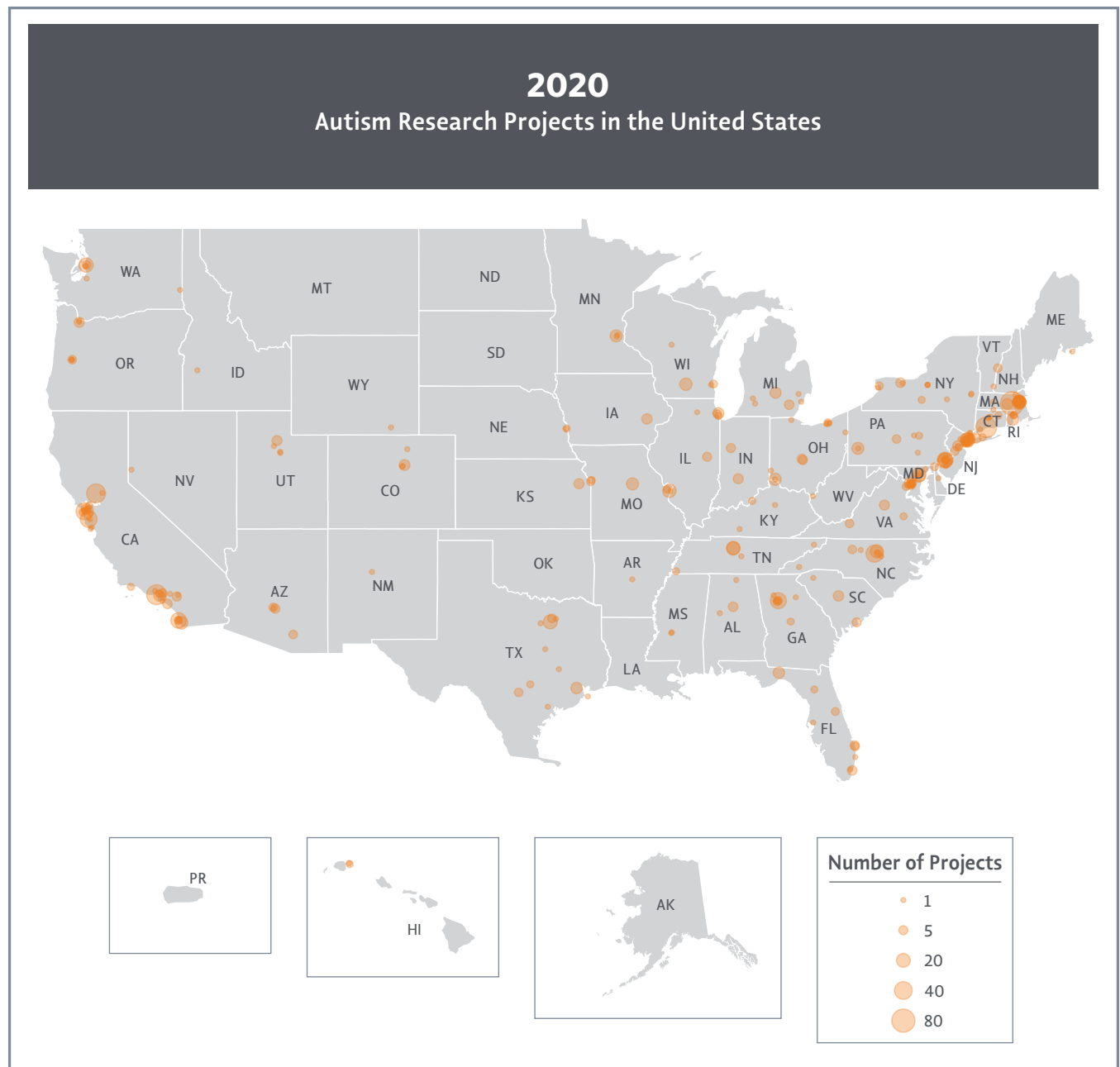
Figure 8. A map of the United States displaying the geographic distribution and number of autism research projects funded by federal agencies and private organizations in 2020.

Which U.S. institutions had the highest levels of funding in 2019 and 2020?					
2019			**2020**		
Institution	Funding Amount	Number of Projects	Institution	Funding Amount	Number of Projects
University of California, Davis	$19,055,796	55	Yale University	$22,230,716	60
Yale University	$18,675,010	59	University of California, Los Angeles	$21,140,137	56
University of California, Los Angeles	$16,411,818	54	University of California, Davis	$19,015,227	48
University of California, San Diego	$14,614,854	34	University of California, San Francisco	$13,425,180	37
National Institutes of Health - Intramural	$12,416,823	9	Stanford University	$13,346,677	33
Stanford University	$11,865,520	33	National Institutes of Health - Intramural	$12,846,533	10
Vanderbilt University	$11,839,693	43	University of California, San Diego	$10,815,459	29
University of California, San Francisco	$11,143,393	40	Vanderbilt University	$10,725,463	37
University of North Carolina at Chapel Hill	$9,644,125	41	Washington University in St. Louis	$9,916,891	18
Washington University in St. Louis	$9,062,734	21	University of North Carolina at Chapel Hill	$9,914,723	38

Table 2. Institutions with the most autism research funding from federal and private sources in 2019 and 2020.

Which states had the highest levels of funding in 2019 and 2020?					
2019			**2020**		
State	Funding Amount	Number of Projects	State	Funding Amount	Number of Projects
California	$93,953,199	301	California	$95,052,698	287
New York	$42,457,087	137	New York	$41,899,517	148
Massachusetts	$38,355,616	244	Maryland	$32,372,192	54
Maryland	$29,964,749	47	Massachusetts	$32,344,358	221
Pennsylvania	$25,336,307	99	Pennsylvania	$25,923,058	105
Connecticut	$21,266,559	67	Connecticut	$24,514,654	66
North Carolina	$19,059,491	69	North Carolina	$18,360,721	66
Tennessee	$13,585,462	47	Georgia	$12,475,254	44
Georgia	$11,663,448	46	Tennessee	$12,145,086	41
New Jersey	$9,281,096	21	Missouri	$11,605,126	35

Table 3. States with the most autism research funding from federal and private sources in 2019 and 2020.

Which countries received autism research funding from U.S. funders?

While the majority of U.S. autism research funding is awarded to investigators at U.S. institutions, several of the funding agencies and organizations invest in autism research internationally. International research was supported by private organizations and the National Institutes of Health and Department of Defense – Army (**Table 4**).

In 2019, researchers in 19 countries outside the United States received support for autism research from U.S. agencies and organizations included in the portfolio analysis, with funding for 79 international projects amounting to $12.4 million (**Table 5**). This accounts for 2.9% of total 2019 funding, and 4.9% of all projects were conducted at international institutions. The countries that received the largest portion of international funding in 2019 were the United Kingdom and Canada.

In 2020, researchers in 18 countries outside the United States received support for autism research, with funding for 65 projects amounting to $11.2 million (**Table 5**). In 2020, 2.7% of total funding went towards institutions outside of the United States, and 4.1% of all projects were conducted at international institutions. As in 2019, the countries that received the largest portion of international funding in 2020 were the United Kingdom and Canada.

U.S. Funders Supporting International Autism Research in 2019 and/or 2020	
Autism Research Institute	Escher Fund for Autism/Escher Family Fund
Autism Speaks	FRAXA Research Foundation
Autism Science Foundation	New England Center for Children
Brain & Behavior Research Foundation	National Institutes of Health
Department of Defense - Army	Simons Foundation

Table 4. U.S. funders of international autism research in 2019 and/or 2020.

COUNTRIES RECEIVING U.S. FUNDING FOR AUTISM RESEARCH IN 2019 AND 2020

Country	2019		2020	
	Funding Amount	Number of Projects	Funding Amount	Number of Projects
Australia	$335,581	6	$392,190	2
Austria	$0	1	$143,873	1
Belgium	$55,800	1	$0	1
Canada	$4,228,595	26	$3,536,508	27
Finland	$20,000	1	$45,000	1
France	$151,764	5	$78,760	1
Germany	$0	0	$35,000	1
Hong Kong	$240,000	1	$120,000	1
Ireland	$17,500	3	$0	0
Israel	$295,800	2	$214,020	2
Italy	$323,340	7	$264,640	7
Kenya	$50,000	1	$8,380	1
Netherlands	$302,947	3	$283,378	2
Qatar	$15,000	1	$0	1
Spain	$0	1	$0	0
Sweden	$35,000	1	$0	1
Switzerland	$302,025	6	$102,500	5
Turkey	$68,200	1	$68,200	1
United Arab Emirates	$2,250	1	$2,250	1
United Kingdom	$5,978,784	11	$5,955,160	9
Total	$12,422,585	79	$11,249,858	65

Table 5. Countries outside of the United States that received funding from U.S. federal agencies or private organizations to support autism research in 2019 and 2020.

How much autism research funding did each funder provide in 2019?

In 2019, the agencies and organizations that participated in the portfolio analysis supported 1,604 autism research projects totaling $424,202,347 (**Table 6**). The National Institutes of Health was the leading federal (and overall) funder of autism research in 2019 with a total of $288.1 million (617 projects). The next largest federal funder was the National Science Foundation, with $19.8 million (45 projects), followed by the Centers for Disease Control and Prevention, with $13.5 million (27 projects). The Simons Foundation and Autism Speaks were the largest private funders of autism research in 2019, with investments of $62.5 million (369 projects) and $4.3 million (51 projects), respectively. The percent of overall autism research investment provided by each funder in 2019 is depicted in **Figure 9**.

2019 AUTISM RESEARCH FUNDING BY AGENCY/ORGANIZATION

Funding Agency/Organization	Funding Amount	Number of Projects
National Institutes of Health (NIH)*	$288,063,533	617
Simons Foundation (SF)	$62,489,357	369
National Science Foundation (NSF)	$19,801,919	45
Centers for Disease Control and Prevention (CDC)	$13,545,901	27
Department of Defense – Army (DoD-Army)	$9,862,348	51
Health Resources and Services Administration (HRSA)**	$7,534,804	42
Department of Education (ED)	$7,347,603	101
Autism Speaks (AS)	$4,335,366	51
Administration for Community Living (ACL)	$2,574,814	11
New Jersey Governor's Council for Medical Research and Treatment of Autism (NJGCA)	$2,200,000	5
Brain & Behavior Research Foundation (BBRF)	$1,502,723	71
Eagles Autism Foundation (Eagles)	$1,280,322	8
Defense Advanced Research Projects Agency (DARPA)	$583,749	1
Agency for Healthcare Research and Quality (AHRQ)	$526,082	3
FRAXA Research Foundation (FRAXA)	$500,000	18
Patient-Centered Outcomes Research Institute (PCORI)	$487,962	7
Els for Autism Foundation (ELS)	$364,036	7
New England Center for Children (NECC)	$311,150	94
Autism Science Foundation (ASF)	$227,000	28
Organization for Autism Research (OAR)	$197,292	18
Tuberous Sclerosis Alliance (TSCA)	$178,424	4
Autism Research Institute (ARI)	$170,200	13
Escher Fund for Autism/Escher Family Fund (EFA)	$55,000	3
Thrasher Research Fund (Thrasher)	$27,762	5
Institute of Museum and Library Services (IMLS)	$25,000	2
Social Security Administration (SSA)	$10,000	1
Environmental Protection Agency (EPA)	$0	1
National Endowment for the Arts (NEA)	$0	1
Total	**$424,202,347**	**1,604**

*NIH autism projects included in the present IACC Portfolio Analysis Report may differ from the projects listed in the "autism" spending category of NIH's **Research, Condition, and Disease Categorization (RCDC)** system. While the RCDC list of autism projects informed the projects included in the present report, variations may exist due to differences in inclusion criteria. Additionally, the NIH project number shown reflects unique NIH projects. Portions of a project funded by more than one NIH institute ("co-funds") were combined and only counted as a single project. This approach differs from that used in the NIH **RePORT** database, where each co-fund portion is counted as a separate project.

** The annual funding amount for some projects reported by HRSA are prorated estimates for the autism-related portion of a larger project.

Table 6. Total funding and number of projects provided by federal agencies and private organizations included in the portfolio analysis for 2019. Together, the agencies and organizations funded 1,604 projects, representing an overall investment of $424.2 million.

2019
Percent of Autism Research Funding by Funder
Total Funding: $424,202,347
Number of Projects: 1,604

*Other includes federal and private funders that account for less than 1% of total autism research funding; these funders and their percentages are: ACL (0.6%), NJGCA (0.5%), BBRF (0.4%), Eagles (0.3%), DARPA (0.1%), AHRQ (0.1%), FRAXA (0.1%), PCORI (0.1%), ELS (0.09%), NECC (0.07%), ASF (0.05%), OAR (0.05%), TSCA (0.04%), ARI (0.04%), EFA (0.01%), Thrasher (0.007%), IMLS (0.006%), SSA (0.002%), EPA (0%), and NEA (0%).

Figure 9. Percent of total autism research funding contributed by federal agencies and private organizations in 2019. The National Institutes of Health provided the largest proportion of funding (67.9%), while the Simons Foundation provided the largest private investment (14.7%).

How much autism research funding did each funder provide in 2020?

In 2020, the agencies and organizations that participated in the portfolio analysis supported 1,573 autism research projects totaling $418,915,385 (**Table 7**). The National Institutes of Health continued to lead federal and overall autism research funding in 2020, with a total of $285.5 million (598 projects). The next largest federal funder was the Centers for Disease Control and Prevention, with $14.1 million (19 projects),

followed by the Department of Defense – Army, with $14.0 million (59 projects). The Simons Foundation and Autism Speaks were the largest private funders of autism research in 2020, with investments of $56.1 million (354 projects) and $7.1 million (83 projects), respectively. The percent of overall autism research investment provided by each funder in 2020 is depicted in **Figure 10**.

2020 AUTISM RESEARCH FUNDING BY AGENCY/ORGANIZATION

Funding Agency/Organization	Funding Amount	Number of Projects
National Institutes of Health (NIH)*	$285,474,136	598
Simons Foundation (SF)	$56,085,170	354
Centers for Disease Control and Prevention (CDC)	$14,143,700	19
Department of Defense – Army (DoD-Army)	$14,002,309	59
Department of Education (ED)	$11,501,480	92
National Science Foundation (NSF)	$9,549,918	50
Autism Speaks (AS)	$7,092,198	83
Health Resources and Services Administration (HRSA)**	$6,942,278	50
Eagles Autism Foundation (Eagles)	$2,951,505	18
Administration for Community Living (ACL)	$2,744,441	12
Patient-Centered Outcomes Research Institute (PCORI)	$2,604,364	6
Brain & Behavior Research Foundation (BBRF)	$1,028,000	49
BRAIN Foundation (BRAIN)	$930,000	8
New Jersey Governor's Council for Medical Research and Treatment of Autism (NJGCA)	$800,000	5
Agency for Healthcare Research and Quality (AHRQ)	$598,119	2
FRAXA Research Foundation (FRAXA)	$480,000	11
Institute of Museum and Library Services (IMLS)	$476,568	3
New England Center for Children (NECC)	$301,816	84
Autism Research Institute (ARI)	$263,850	14
Food and Drug Administration (FDA)	$249,430	1
Organization for Autism Research (OAR)	$159,991	17
National Endowment for the Arts (NEA)	$149,943	2
Els for Autism Foundation (ELS)	$149,435	7
Tuberous Sclerosis Alliance (TSCA)	$113,659	3
Autism Science Foundation (ASF)	$59,000	19
Escher Fund for Autism/Escher Family Fund (EFA)	$30,000	2
Thrasher Research Fund (Thrasher)	$24,075	2
Social Security Administration (SSA)	$10,000	2
Defense Advanced Research Projects Agency (DARPA)	$0	1
Total	**$418,915,385**	**1,573**

*NIH autism projects included in the present IACC Portfolio Analysis Report may differ from the projects listed in the "autism" spending category of NIH's **Research, Condition, and Disease Categorization (RCDC)** system. While the RCDC list of autism projects informed the projects included in the present report, variations may exist due to differences in inclusion criteria. Additionally, the NIH project number shown reflects unique NIH projects. Portions of a project funded by more than one NIH institute ("co-funds") were combined and only counted as a single project. This approach differs from that used in the NIH **RePORT** database, where each co-fund portion is counted as a separate project.

** The annual funding amount for some projects reported by HRSA are prorated estimates for the autism-related portion of a larger project.

Table 7. Funding and number of projects provided by federal agencies and private organizations included in the portfolio analysis for 2020. Together, the agencies and organizations funded 1,573 projects, reflecting an overall investment of $418.9 million.
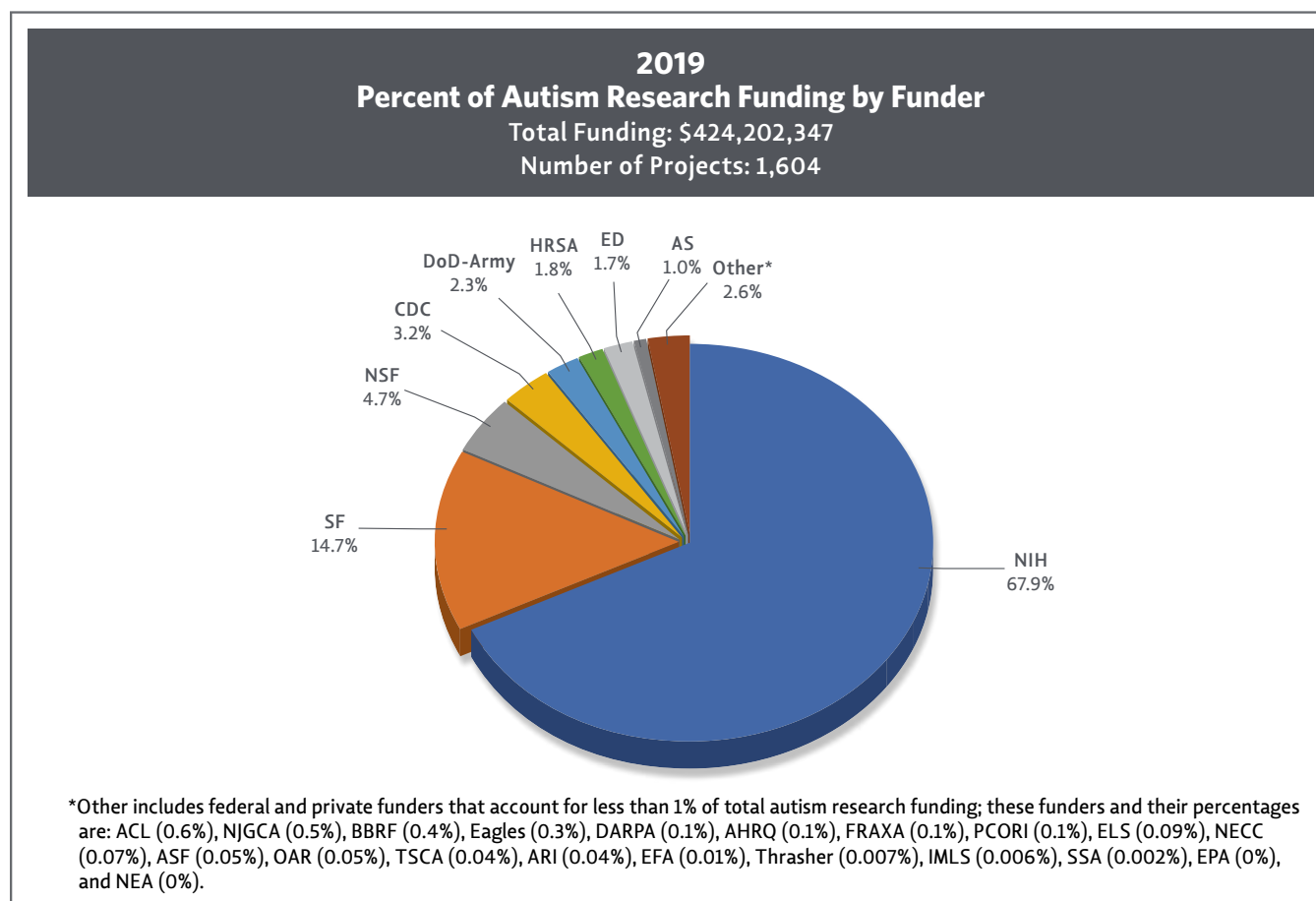
2020
Percent of Autism Research Funding by Funder
Total Funding: $418,915,385
Number of Projects: 1,573
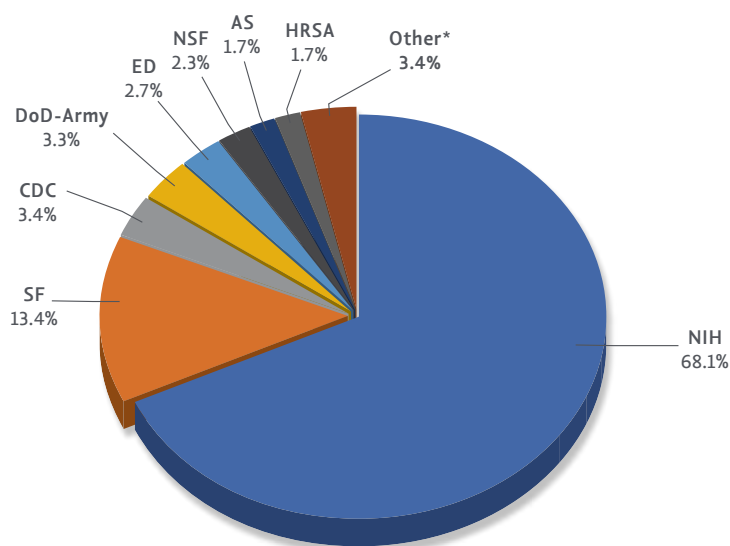
*Other includes federal and private funders that account for less than 1% of total autism research funding; these funders and their percentages are: Eagles (0.7%), ACL (0.7%), PCORI (0.6%), BBRF (0.2%), BRAIN (0.2%), NJGCA (0.2%), AHRQ (0.1%), FRAXA (0.1%), IMLS (0.1%), NECC (0.07%), ARI (0.06%), FDA (0.06%), OAR (0.04%), NEA (0.04%), ELS (0.04%), TSCA (0.03%), ASF (0.01%), EFA (0.007%), Thrasher (0.006%), SSA (0.002%), and DARPA (0%).

Figure 10. Percent of total autism research funding contributed by federal agencies and private organizations in 2020. The National Institutes of Health provided the largest proportion of funding (68.1%), while the Simons Foundation provided the largest private investment (13.4%).

Summary of Autism Research Funding in 2019 and 2020

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 this was an ambitious goal but believed that such an increase could also have a significant impact if achieved. Since the *2016 Portfolio Analysis Report*, funding for autism research increased from $364.4 million in 2016 to $424.2 million in 2019, reflecting a 16.4% ($59.8 million) increase. From 2019 to 2020 ($418.9 million), autism funding decreased by 1.2% ($5.3 million). In comparison to 2016, however, 2020 funding reflects an increase of 14.9% ($54.5 million). While this did not meet the *2016-2017 IACC Strategic Plan* recommended yearly 15% increase, which would have resulted in an estimated funding amount of $685 million in 2020, autism research did experience a substantial growth in funding during this period (**Figure 11**). The addition of newly established funders to the portfolio such as the Eagles Autism Foundation and the BRAIN Foundation indicates that autism continues to be an area of research attention and growth.

Future Portfolio Analysis Reports will continue to closely monitor funding in support of autism research, as well as track growth in high-priority areas as identified by the IACC. As described in the Budget Recommendation of the new ***2021-2023 IACC Strategic Plan for Autism Research, Services, and Policy***, the Committee has called for increased funding for research on lifespan issues (e.g., transition to adulthood, higher education, employment, housing, health care, lifelong learning, community integration, and healthy aging), evidence-based interventions and services, and disparities and the development of culturally responsive tools and services. While all aspects of the autism research portfolio require increases in funding, these are just a few of the areas identified by the IACC that are in particular need of resource growth. The new Strategic Plan also highlights priorities for supporting autistic individuals across the spectrum, including those with the highest support needs, and across the lifespan, including older adulthood, as well as ways to improve mental and physical health; increase accessibility of services, interventions, and research; and greater acceptance and inclusion of autistic individuals. These topics are further discussed in the *2021-2023 IACC Strategic Plan*.

Total U.S. Autism Research Funding Compared to IACC Budget Recommendations
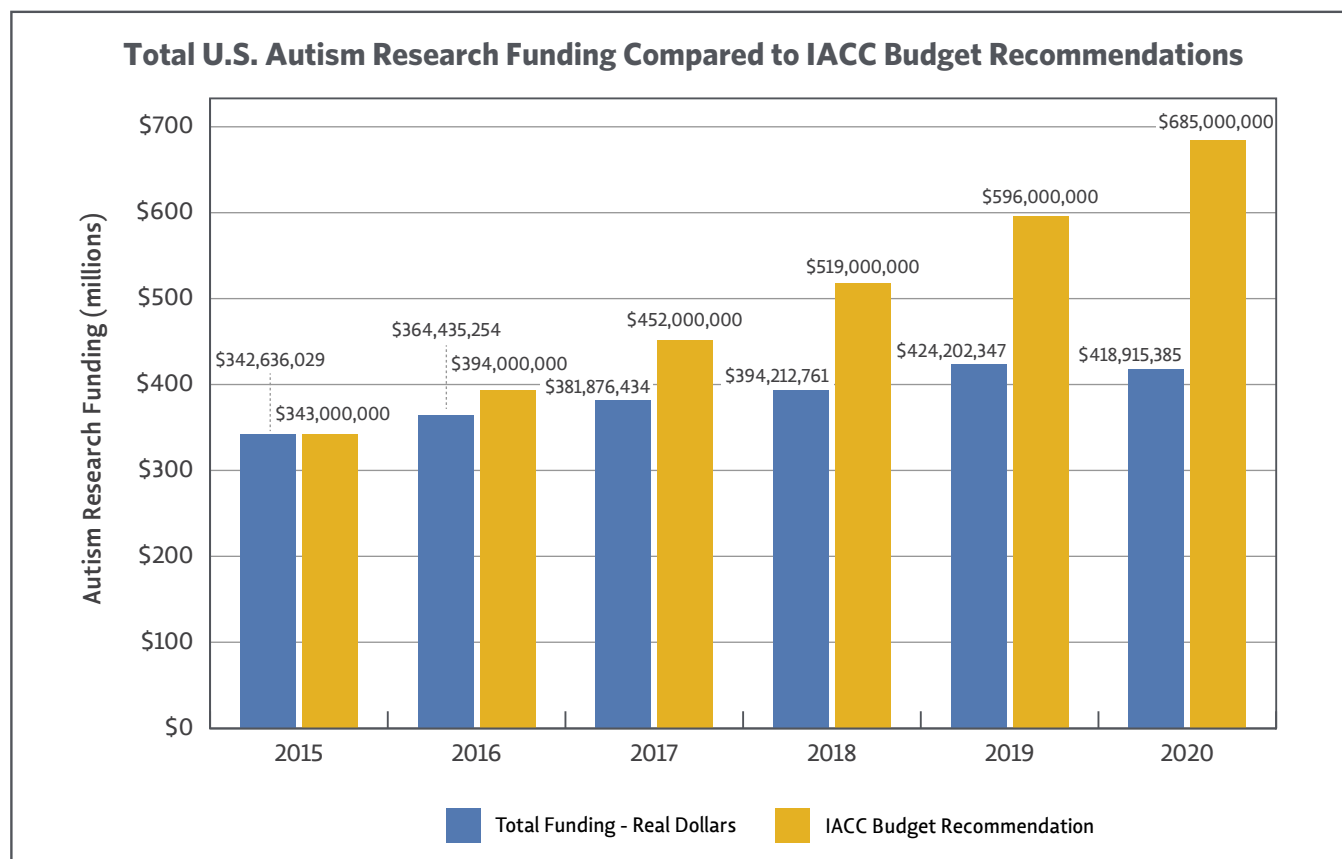

Figure 11. The IACC recommended a doubling of the combined federal and private autism research budget to $685 million by 2020 in the *2016-2017 IACC Strategic Plan*. Based on 2019 and 2020 funding amounts, autism research investment is increasing but did not meet the IACC Budget Recommendation.

AUTISM RESEARCH AREAS AND ANALYSES OF FUNDING OVER TIME

Which areas of autism research were funded in 2019 and 2020?

To better understand which areas of research were funded in 2019 and 2020, projects were aligned with the seven Questions of the *2016-2017 IACC Strategic Plan*. **Figures 12** and **13** illustrate the breakdown of research funding per each of the Strategic Plan's Question areas, which are: Screening and Diagnosis (Question 1), Biology (Question 2), Genetic and Environmental Factors (Question 3), Interventions (Question 4), Services and Supports (Question 5), Lifespan (Question 6), and Infrastructure and Prevalence (Question 7). Identifying how research investments correspond to the Strategic Plan provides an understanding of how funders have directed investments to priority areas identified by the IACC, as well as an indication of which areas are well-supported versus those that may need additional attention or development.

Autism research funding in 2019 and 2020 supported projects relevant to all seven Questions in the IACC Strategic Plan. For both 2019 and 2020, the largest portion of funding addressed the underlying Biology of autism (Question 2). This was followed by Question 3 (Genetic and Environmental Factors), research aimed at identifying potential factors that may contribute to autism. In 2019, the percent of total funding aligned with each Question were as follows: Question 1, 5.4%; Question 2, 45.3%; Question 3, 19.3%; Question 4, 11.1%; Question 5, 4.9%; Question 6, 4.3%; Question 7, 9.8% (**Figure 12**). Similarly, in 2020, the percent of total funding aligned with each Question were: Question 1, 7.1%; Question 2, 45.4%; Question 3, 17.5%; Question 4, 8.6%; Question 5, 8.4%; Question 6, 4.3%; Question 7, 8.7% (**Figure 13**).

2019
Autism Research Funding by IACC Strategic Plan Question
Total Funding: $424,202,347

Q7. Infrastructure and Prevalence
$41,368,724
9.8%

Q1. Screening and Diagnosis
$22,878,014
5.4%

Q6. Lifespan
$18,056,226
4.3%

Q5. Services and Supports
$20,670,124
4.9%

Q4. Interventions
$46,978,391
11.1%

Q2. Biology
$192,267,350
45.3%

Q3. Genetic and Environmental Factors
$81,983,518
19.3%

Figure 12. Distribution of 2019 autism research funding by IACC Strategic Plan Question. The seven Questions of the Strategic Plan are represented in the clockwise direction, beginning with Screening and Diagnosis (Question 1) and ending with Infrastructure and Prevalence (Question 7).

2020
Autism Research Funding by IACC Strategic Plan Question
Total Funding: $418,915,385

Q7. Infrastructure and Prevalence
$36,293,536
8.7%

Q1. Screening and Diagnosis
$29,896,564
7.1%

Q6. Lifespan
$17,969,273
4.3%

Q5. Services and Supports
$35,303,767
8.4%

Q2. Biology
$190,289,259
45.4%

Q4. Interventions
$35,836,890
8.6%

Q3. Genetic and Environmental Factors
$73,326,095
17.5%

Figure 13. Distribution of 2020 autism research funding by IACC Strategic Plan Question. The seven Questions of the Strategic Plan are represented in the clockwise direction, beginning with Screening and Diagnosis (Question 1) and ending with Infrastructure and Prevalence (Question 7).

Another way to evaluate the autism research landscape is to measure the number of research projects funded. When the number of projects is considered, the proportions of each Question area shift due to differences in the relative size and cost of projects falling under each of the topics. In particular, research on Interventions (Question 4) and Services and Supports (Question 5) have greater portions of the whole when the number of projects is considered versus dollar amounts. In 2019, the percent of total projects aligned with each Question were as follows:

Question 1, 5.7%; Question 2, 38.6%; Question 3, 14.5%; Question 4, 17.1%; Question 5, 8.9%; Question 6, 5.6%; Question 7, 9.6% (**Figure 14**). The percent of total projects aligned with each Question were similar in 2020: Question 1, 6.7%; Question 2, 37.5%; Question 3, 14.2%; Question 4, 15.1%; Question 5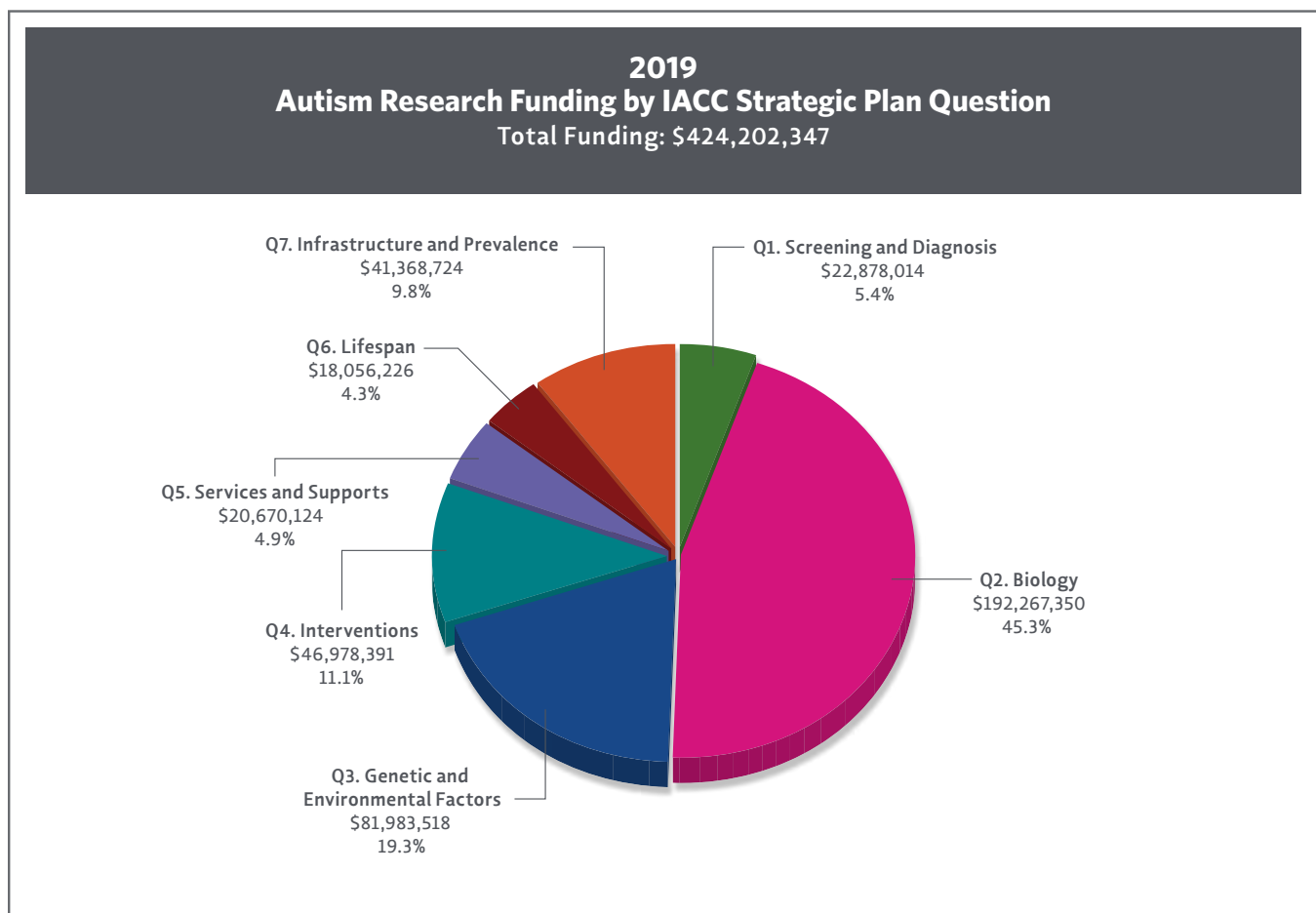, 11.4%; Question 6, 6.0%; Question 7, 9.1% (**Figure 15**). Overall, the proportion of projects in each Question area remained relatively constant from one year to the next.

2019
Number of Autism Research Projects by IACC Strategic Plan Question
Total Number of Projects: 1,604

Q7. Infrastructure and Prevalence
154 projects
9.6%

Q1. Screening and Diagnosis
91 projects
5.7%

Q6. Lifespan
90 projects
5.6%

Q5. Services and Supports
142 projects
8.9%

Q2. Biology
619 projects
38.6%

Q4. Interventions
275 projects
17.1%

Q3. Genetic and Environmental Factors
233 projects
14.5%

Figure 14. Number of autism research projects by IACC Strategic Plan Question in 2019.

2020
Number of Autism Research Projects by IACC Strategic Plan Question
Total Number of Projects: 1,573

Q7. Infrastructure and Prevalence
143 projects
9.1%

Q6. Lifespan
95 projects
6.0%

Q5. Services and Supports
179 projects
11.4%

Q1. Screening and Diagnosis
105 projects
6.7%

Q2. Biology
590 projects
37.5%

Q4. Interventions
237 projects
15.1%

Q3. Genetic and Environmental Factors
224 projects
14.2%
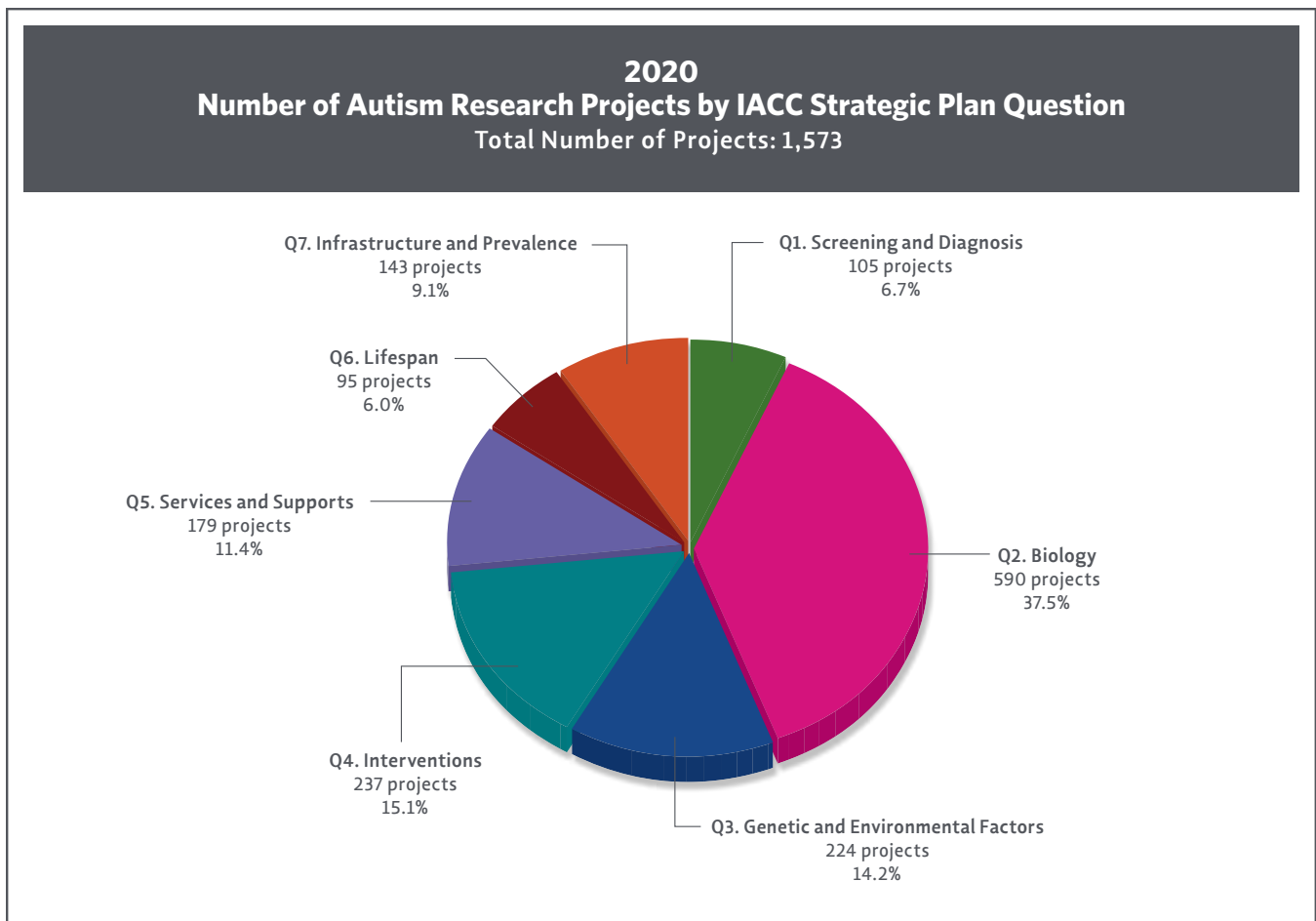
Figure 15. Number of autism research projects by IACC Strategic Plan Question in 2020.

How has funding for different areas of autism research changed from 2008 to 2020?

The IACC has been tracking how autism research funding and projects align with IACC Strategic Plan Questions for 13 years. **Figure 16** shows the funding amount for each Question over time in real dollars (even when adjusted for inflation, the trajectories of growth over time remain the same for each of the seven Question areas). **Figure 17** shows the number of projects for each Question area from 2008 to 2020.

Research funding and the number of projects for Question 2 (Biology) has grown substantially from

2008 to 2020. This Question area now makes up almost half of the U.S. autism research portfolio. In 2008, Question 3 (Genetic and Environmental Factors) received the largest amount of funding compared to other Question areas. However, funding and the number of projects for this Question decreased from 2009 to 2014. Since 2014, there has been renewed growth in Question 3 research, and it is the second largest Question area in the U.S. autism research portfolio. Funding for Question 4 (Interventions)
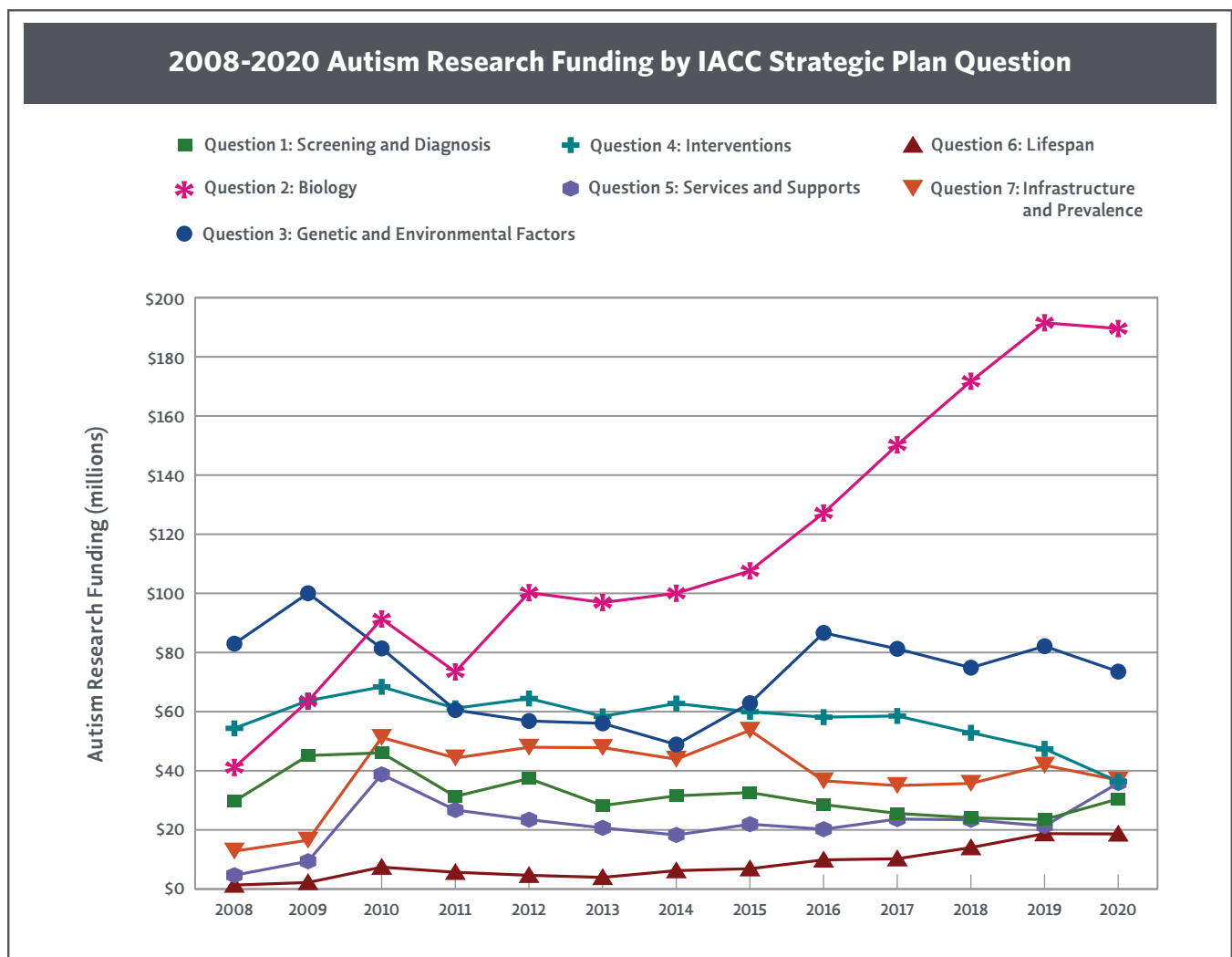
Figure 16. Autism research funding from 2008 to 2020 by IACC Strategic Plan Question.

remained mostly stable between 2008-2017, though the number of projects did decrease between 2015 and 2016 due to a change in coding to better align projects with the updated Objectives of the *2016-2017 Strategic Plan* (see **page 63** for more details). Since 2017, there has been a decrease in the dollar amount of Question 4 funding, but the number of projects did not decrease from 2017-2019. Question 5 (Services and Supports) and Question 6 (Lifespan) have historically been the areas that receive the lowest amounts of funding. In

recent years, however, funding and the number of projects for both Question areas have been on the rise. Lastly, funding amounts and the number of projects for Question 1 (Screening and Diagnosis) and Question 7 (Infrastructure and Prevalence) have been relatively consistent over the 13-year span.

Subsequent sections in this report provide in-depth analyses of changes in funding over time (2008-2020) for each Question area.
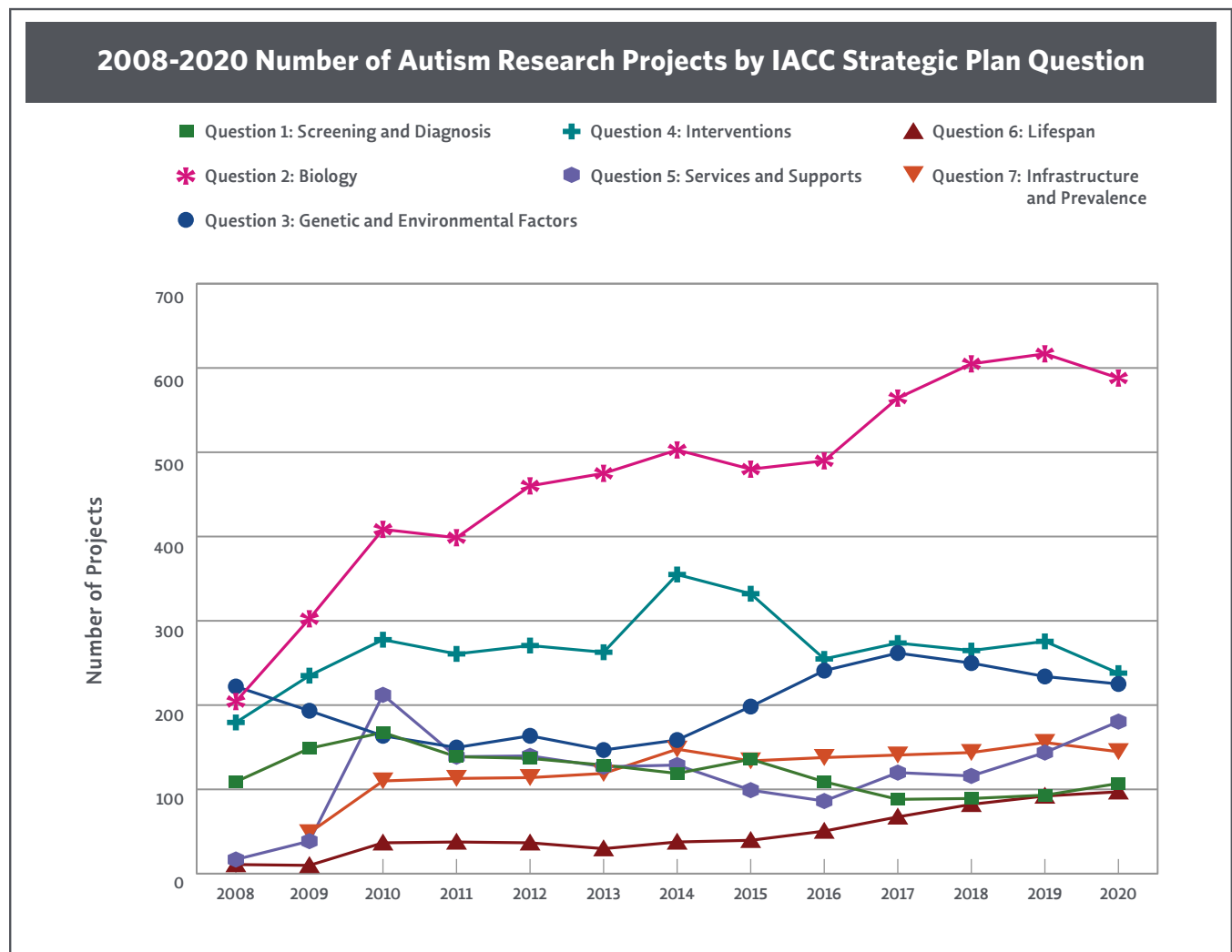
Figure 17. The number of autism research projects from 2008 to 2020 by IACC Strategic Plan Question.

How many new autism research projects were added to each Question area in 2019 and 2020 compared to ongoing research?

When comparing Strategic Plan Questions, the proportion of new versus ongoing projects is not consistent across all areas of autism research. In comparison to other Question areas, research related to Lifespan (Question 6) and Services and Supports (Question 5) had higher proportions of funding devoted to new projects in 2019 and 2020 (**Figure 18**). The IACC has emphasized the need to expand research in these areas, highlighted in the *2016-2017 IACC Strategic Plan's* Budget Recommendation. While Question 5 and Question 6 have historically received the least funding compared to other Question areas,

the high proportion of newly funded projects on these topics suggests growth that aligns with Strategic Plan recommendations. In contrast, funding for Biology (Question 2) and Genetic and Environmental Factors (Question 3) had the highest proportions of funding going to ongoing projects when compared to other Questions. These two Question areas have historically received the highest amounts of funding and are well established, with many ongoing projects from year-to-year. Future Portfolio Analysis Reports will continue to monitor trends in the distribution of new versus ongoing projects across the portfolio.
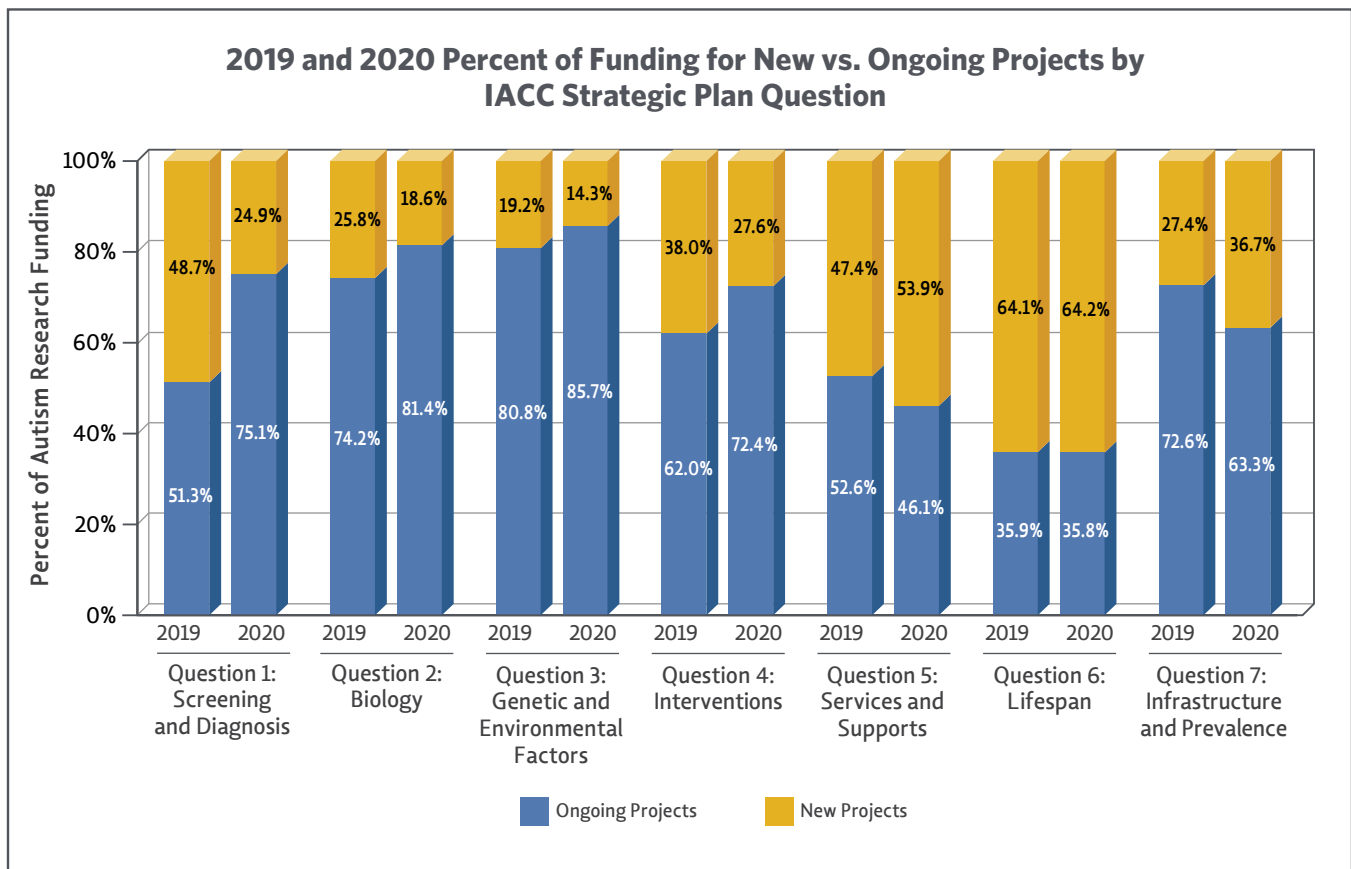
Figure 18. Percent of 2019 and 2020 autism research funding directed to ongoing versus new projects varies by Strategic Plan Question area.

What types of autism research are funded by the different agencies and organizations?

The 14 federal and 16 private funders included in the Portfolio Analysis Report fund a wide range of autism research projects. As shown in **Figure 19**, federal and private funders contributed to funding for each of the Question areas in the IACC Strategic Plan in 2019 and 2020. However, the amount of federal and private funding varies by Question area, as some areas align more closely with federal or private mission areas and priorities. All Question areas received more federal funding than private funding. The research areas that received the largest amounts of federal funding were Biology (Question 2), Genetic and Environmental Factors (Question 3), and Interventions (Question 4). The research areas that received the largest amounts of private funding were Biology (Question 2), Infrastructure and Prevalence (Question 7), and Genetic and Environmental Factors (Question 3).

2019 and 2020 Federal and Private Investments by IACC Strategic Plan Question
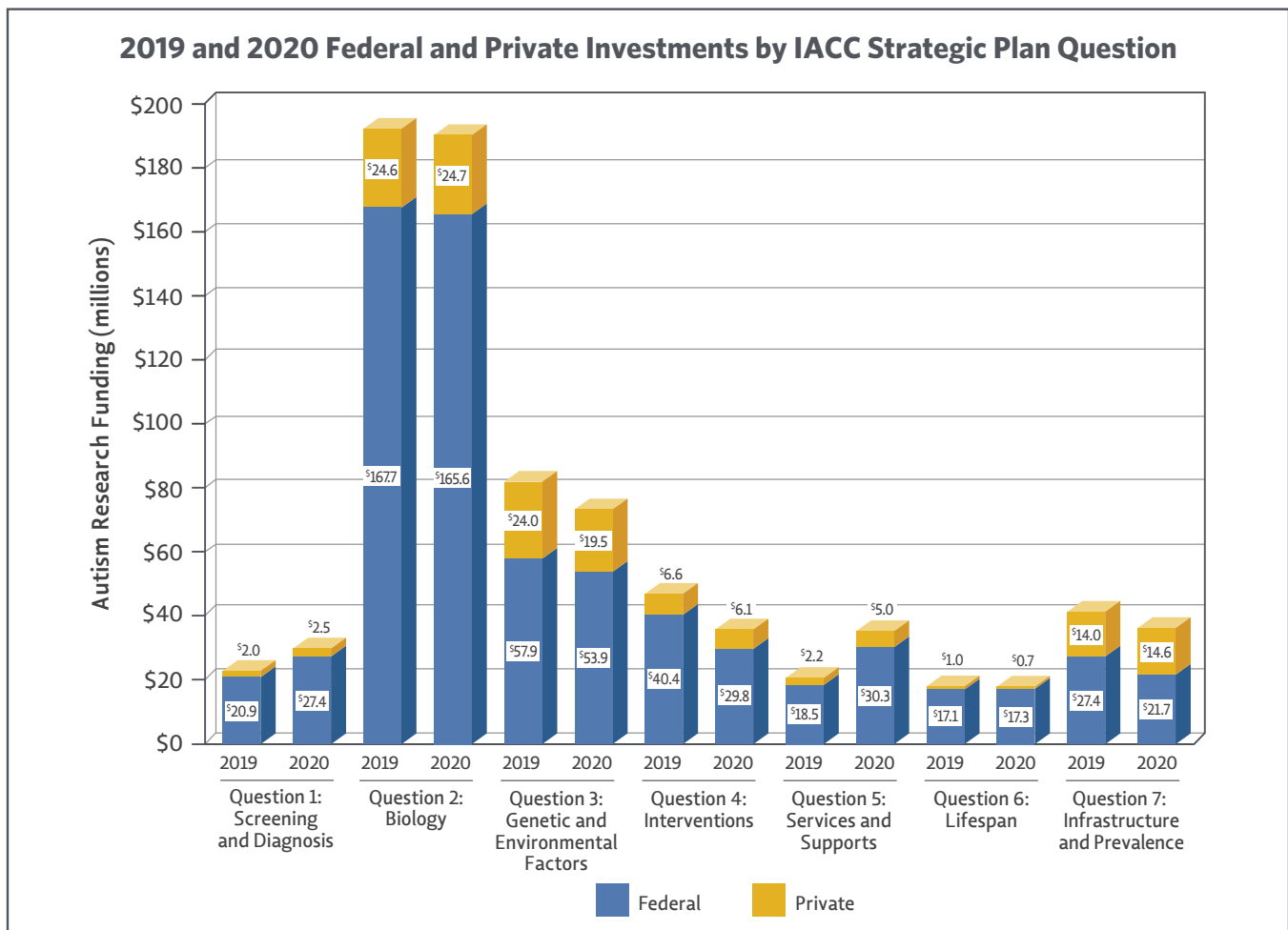
Figure 19. Federal and private funding was provided for each Strategic Plan Question area in 2019 and 2020, although the amount of federal and private funding varied between Question areas. Funding amounts in this figure are rounded to nearest tenth of a million. See **Table 11** in Appendix A for full funding amounts.

Figure 20 shows the agencies and organizations that funded projects in each of the seven Question areas of the Strategic Plan in 2019 and 2020. **Figures 21** and **22** illustrate the breadth of the mission areas of funding agencies and organizations included in the Portfolio Analysis Report. These figures demonstrate that while some agencies and organizations have broad portfolios that cover many different research areas described in the Strategic Plan, others focus their efforts on a narrower range of research topics.
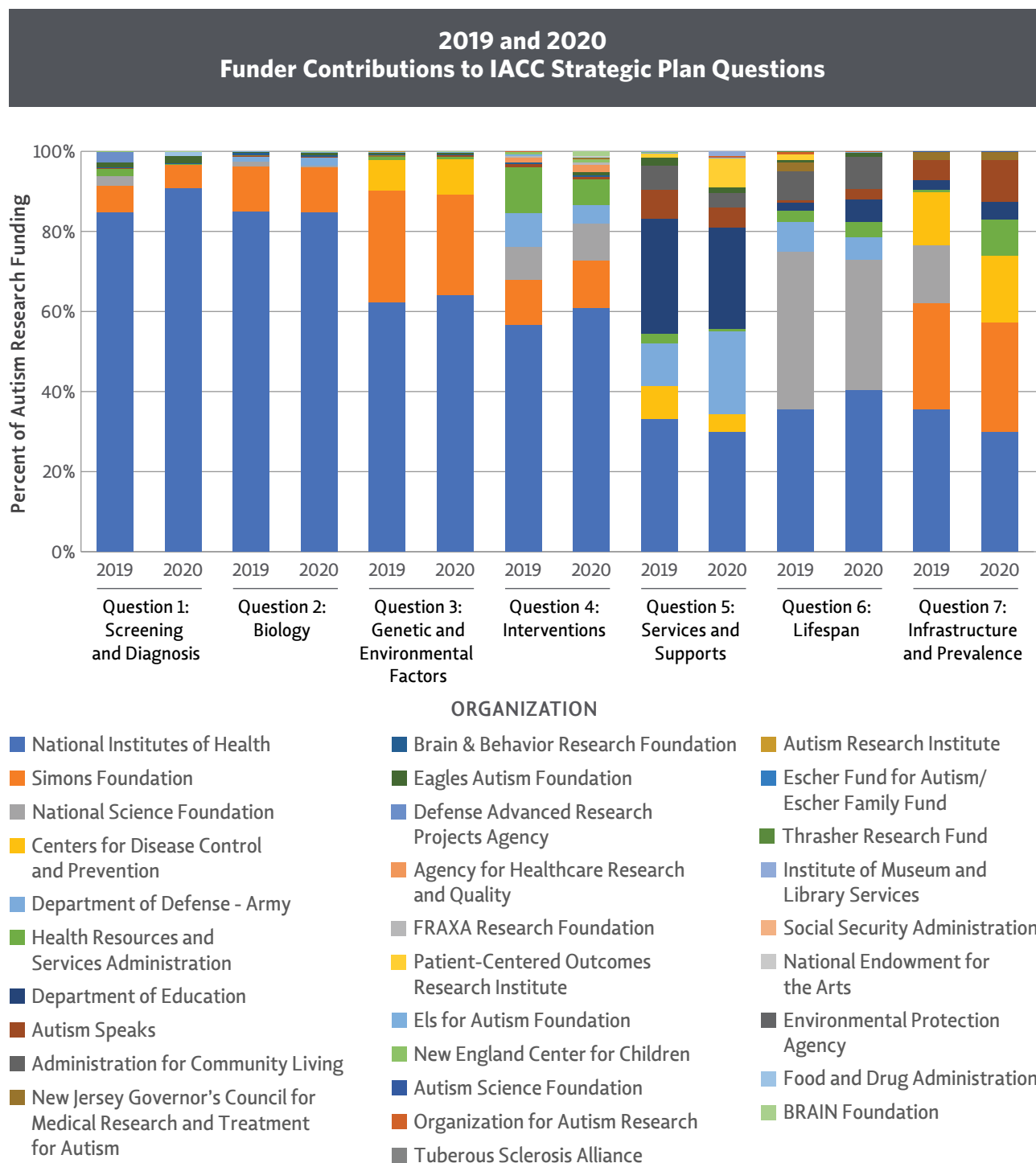
Figure 20. The relative contributions of federal agencies and private organizations to each IACC Strategic Plan Question in 2019 and 2020.

2019
Distribution of Funder Portfolios across IACC Strategic Plan Questions

Question 1: Screening and Diagnosis
Question 2: Biology
Question 3: Genetic and Environmental Factors
Question 4: Interventions
Question 5: Services and Supports
Question 6: Lifespan
Question 7: Infrastructure and Prevalence
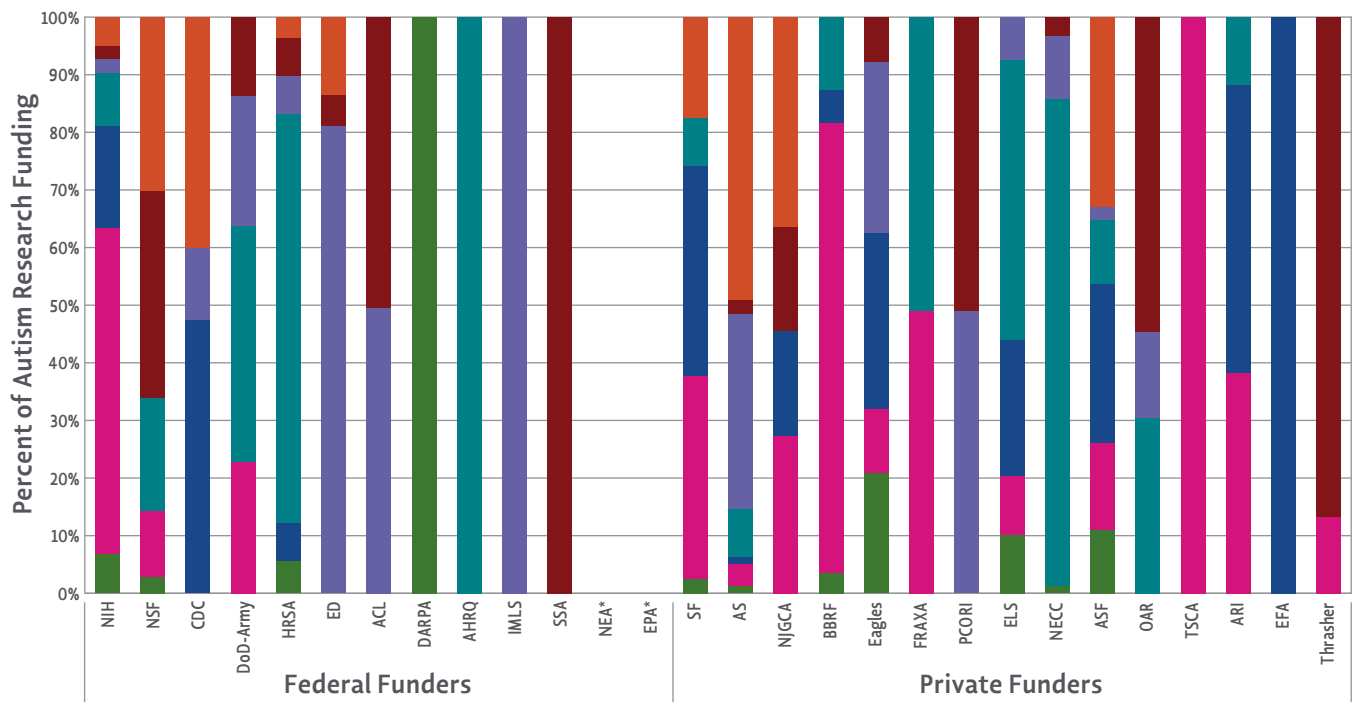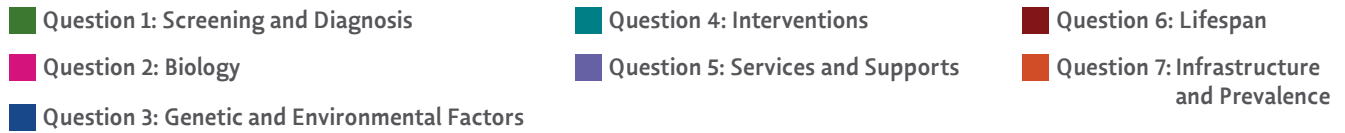
* In 2019, NEA and EPA each had one active research project, but all funds for the projects had been disbursed in prior years.

Figure 21. The portfolio of each federal agency and private organization's 2019 autism research funding by Strategic Plan Question. Please note that this figure is based on funding amounts for 2019. Thus, while funders may support additional areas of research, this may not be reflected in this particular year of analysis.

**2020
Distribution of Funder Portfolios across IACC Strategic Plan Questions**
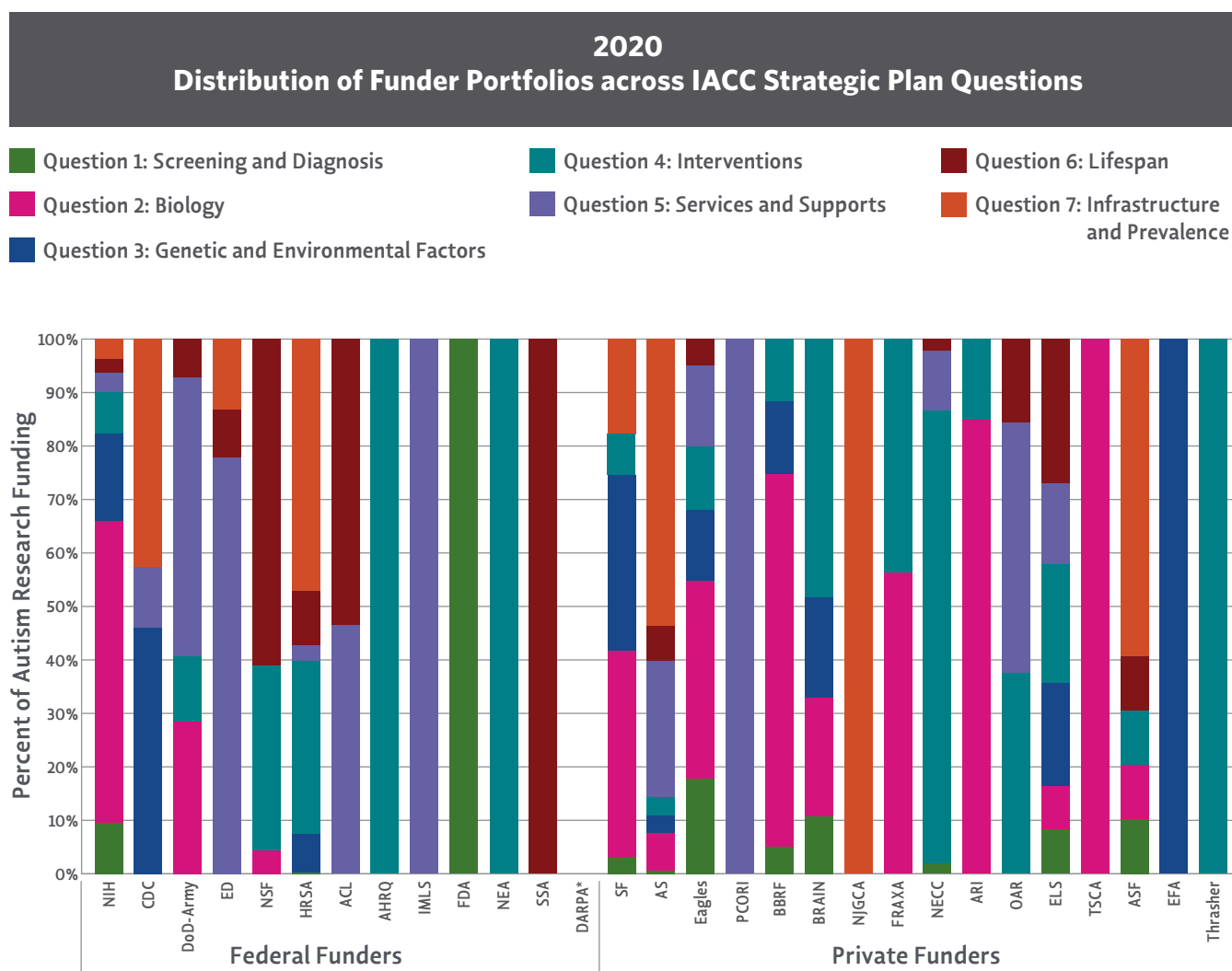
* In 2020, DARPA had one ongoing research project, but all funds for this project were disbursed in prior years.

Figure 22. The portfolio of each federal agency and private organization's 2020 autism research funding by Strategic Plan Question. Please note that this figure is based on funding amounts for 2020. Thus, while funders may support additional areas of research, this may not be reflected in this particular year of analysis.

How did the autism research projects funded in 2019 and 2020 align with the Objectives in the IACC Strategic Plan?

The Strategic Plan Objectives were developed by the IACC to set priorities for investment. Autism research projects in 2019 and 2020 were reviewed by ONAC and the funder and matched with a Question and research

Objective in the *2016-2017 IACC Strategic Plan*. In some cases, a given project did not fit closely with any of the Strategic Plan Objectives and could only be assigned to a broader Strategic Plan Question. Those projects were

designated as "Core/Other" rather than assigned to a specific Objective. The Core/Other category captures projects that may be related to "core" activities that help support the autism research field, projects in well-established areas of science that do not fit within the parameters of the specific research Objectives, or emerging areas of research. The Core/Other designation was developed by the IACC because the Committee felt it would help readers understand that even though activities in this category fall outside the specific research Objectives of the Strategic Plan, they represent projects that are contributing in important ways to autism research. Subsequent sections of this report provide in-depth Subcategory analyses for each Question of the Strategic Plan, which provide

a description of the research areas addressed by all projects, including those assigned to Core/Other.

The proportion of projects that fit within Strategic Plan Objectives versus the proportion that did not fit within Strategic Plan Objectives are shown in **Figure 23**. In 2019, 3.2% ($13.5 million) of the funding went to 60 projects that were designated as Core/Other. In 2020, 2.0% ($8.5 million) of the funding went to 41 projects that were designated as Core/Other. These percentages follow closely with 2018's proportion of projects categorized as Core/Other (3.6%). **Figure 24** illustrates the breakdown of funding within each Strategic Plan Question that was specific to the Question Objective or designated as Core/Other.

2019
Autism Research Funding:
Alignment with IACC Strategic Plan Objectives
Total Funding: $424,202,347
Number of Projects: 1,604

Core/Other
$13,492,043
3.2%
60 projects

Specific to Objectives
$410,710,304
96.8%
1,544 projects

2020
Autism Research Funding:
Alignment with IACC Strategic Plan Objectives
Total Funding: $418,915,385
Number of Projects: 1,573

Core/Other
$8,484,880
2.0%
41 projects

Specific to Objectives
$410,430,505
98.0%
1,532 projects

Figure 23. In 2019, 3.2% of funding went to projects that were not specific to a particular IACC Strategic Plan Objective and were designated as Core/Other. In 2020, 2.0% of projects were categorized as Core/Other.

2019 and 2020 Autism Research Funding Alignment with IACC Strategic Plan Objectives
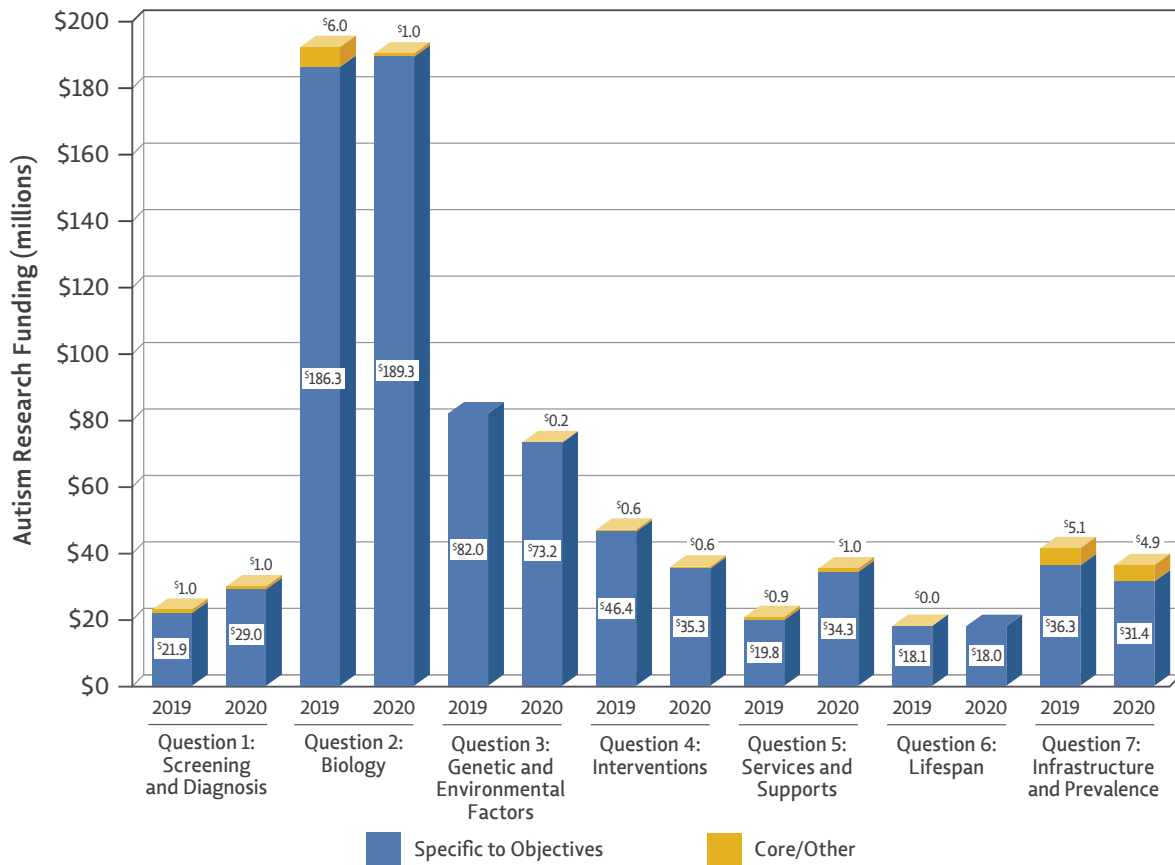
Figure 24. In 2019 and 2020, the majority of funding for autism projects was assigned to a specific Objective within the IACC Strategic Plan Questions. However, each Question in the Strategic Plan contained projects that were not specific to a particular Objective, which were designated as Core/Other. Funding for projects that fall under specific Objectives are indicated in blue, and Core/Other projects are in yellow. Funding amounts in this figure are rounded to the nearest tenth of a million. See **Table 12** in Appendix A for full funding amounts.

ANALYSIS OF FUNDING ADDRESSING IACC STRATEGIC PLAN OBJECTIVES BY RESEARCH AREA

Introduction: IACC Strategic Plan Objectives

The *2016-2017 IACC Strategic Plan* has three to four Objectives in each Question area, plus an additional Cross-Cutting Objective on autism in girls and women, that describe specific research priorities identified by the Committee. There are 23 total Objectives in the *2016-2017 IACC Strategic Plan*. Each autism project that received funding in 2019 and/or 2020 was evaluated to determine which Strategic Plan Question and Objective it fulfilled. In addition, this report also includes information on research funding addressing the Cross-Cutting Theme on Disparities.[2] **Table 8** summarizes the funding amount and number of active projects associated with each Objective and Theme in 2019 and 2020. In addition, **Table 8** provides the Objective/Theme Status for 2019 and 2020; an Objective/Theme was considered "In Progress" if there was at least one associated active project for the year of analysis. All Objectives and the Cross-Cutting Theme on disparities were in progress in both 2019 and 2020. **Table 9** lists the agencies and organizations that provided funding for the Objectives and Cross-Cutting Theme in each year.

Strategic Plan Question	Strategic Plan Objective	2019			2020		
		Status	Funding Amount	Number of Projects	Status	Funding Amount	Number of Projects
Question 1: Screening and Diagnosis	1.1	In Progress	$2,587,942	6	In Progress	$4,372,262	6
	1.2	In Progress	$1,023,262	7	In Progress	$436,679	8
	1.3	In Progress	$18,271,626	75	In Progress	$24,239,291	89
Question 2: Biology	2.1	In Progress	$145,050,853	518	In Progress	$155,128,949	505
	2.2	In Progress	$20,270,300	46	In Progress	$13,071,782	43
	2.3	In Progress	$20,996,091	36	In Progress	$21,139,870	34
Question 3: Genetic and Envirnmental Factors	3.1	In Progress	$39,128,346	143	In Progress	$32,749,495	140
	3.2	In Progress	$7,260,702	27	In Progress	$7,457,722	26
	3.3	In Progress	$35,594,470	63	In Progress	$32,946,144	57
Question 4: Interventions	4.1	In Progress	$21,057,634	86	In Progress	$16,112,753	77
	4.2	In Progress	$16,648,725	135	In Progress	$12,332,691	112
	4.3	In Progress	$8,692,138	51	In Progress	$6,816,100	45
Question 5: Services and Supports	5.1	In Progress	$7,828,594	20	In Progress	$18,607,290	38
	5.2	In Progress	$842,317	16	In Progress	$780,821	22
	5.3	In Progress	$11,124,212	104	In Progress	$14,890,656	116
Question 6: Lifespan	6.1	In Progress	$8,422,797	48	In Progress	$5,693,631	44
	6.2	In Progress	$2,014,246	16	In Progress	$3,013,370	18
	6.3	In Progress	$7,619,083	24	In Progress	$9,262,273	33
Question 7: Infrastructure and Prevalence	7.1	In Progress	$5,588,936	19	In Progress	$7,597,792	31
	7.2	In Progress	$12,279,497	24	In Progress	$8,357,209	20
	7.3	In Progress	$12,985,534	62	In Progress	$9,381,827	57
	7.4	In Progress	$5,423,000	18	In Progress	$6,041,899	11
Cross-Cutting	Autism in Girls and Women	In Progress	$6,962,755	32	In Progress	$8,302,759	23
	Disparities	In Progress	$27,964,376	94	In Progress	$24,014,845	94

Table 8. Summary of 2019 and 2020 Objective status, funding, and number of projects for each Objective listed in the *2016-2017 IACC Strategic Plan* and for the Cross-Cutting Theme on Disparities. An Objective/Theme was considered "In Progress" if there was at least one active project associated for the year of analysis. See **Figure 1** for the full text of all Objectives and the Cross-Cutting Theme.

---

2 Though the *2016-2017 IACC Strategic Plan* does not include a formal Cross-Cutting Objective on disparities, the Committee began tracking research in this area beginning in the *2017-2018 IACC Portfolio Analysis Report*. The IACC created and added a formal Cross-Cutting Recommendation on diversity, equity, inclusion, and accessibility to the recently published *2021-2023 IACC Strategic Plan*, and future Portfolio Analysis Reports will continue to provide analysis of the funding and number of projects focused on these important topics.

Strategic Plan Question	Strategic Plan Objective	2019 Funders	2020 Funders
Question 1: Screening and Diagnosis	1.1	ASF, HRSA, NIH, SF	HRSA, NIH, SF
	1.2	HRSA, NIH	HRSA, NECC, NIH
	1.3	ASF, AS, BBRF, DARPA, Eagles, ED, ELS, HRSA, NECC, NIH, NSF, SF	ASF, AS, BBRF, BRAIN, DARPA, Eagles, ED, ELS, FDA, HRSA, NECC, NIH, NSF, SF
Question 2: Biology	2.1	ARI, ASF, AS, BBRF, DoD-Army, ELS, FRAXA, HRSA, NIH, NJGCA, NSF, SF, Thrasher, TSCA	ARI, ASF, AS, BBRF, BRAIN, DoD-Army, Eagles, ELS, FRAXA, HRSA, NIH, NJGCA, NSF, SF, TSCA
	2.2	ASF, AS, DoD-Army, Eagles, HRSA, NIH, NSF, SF	ARI, ASF, AS, DoD-Army, Eagles, HRSA, NIH, SF
	2.3	ASF, AS, NIH, SF, Thrasher, TSCA	ASF, AS, NIH, SF, TSCA
Question 3: Genetic and Envirnmental Factors	3.1	ARI, ASF, AS, BBRF, Eagles, ELS, NIH, NJGCA, SF	ARI, ASF, AS, BBRF, BRAIN, Eagles, ELS, NIH, NJGCA, SF
	3.2	ARI, AS, DoD-Army, Eagles, HRSA, NIH, SF	ARI, AS, BBRF, DoD-Army, Eagles, HRSA, NIH, SF
	3.3	ASF, BBRF, CDC, DoD-Army, EFA, EPA, NIH, SF	ASF, BBRF, BRAIN, CDC, DoD-Army, EFA, NIH, SF
Question 4: Interventions	4.1	AHRQ, ARI, ASF, AS, BBRF, DoD-Army, ELS, FRAXA, HRSA, NECC, NIH, NSF, SF	AHRQ, ARI, ASF, AS, BBRF, BRAIN, DoD-Army, ELS, FRAXA, HRSA, NECC, NIH, NSF, SF, Thrasher
	4.2	ARI, AS, DoD-Army, ED, ELS, HRSA, NEA, NECC, NIH, NSF, OAR, PCORI	ARI, ASF, AS, DoD-Army, Eagles, ED, ELS, HRSA, NEA, NECC, NIH, NSF, OAR
	4.3	ACL, ASF, DoD-Army, ED, HRSA, NECC, NIH, NSF, OAR, SF, Thrasher	ACL, ASF, DoD-Army, ED, HRSA, NECC, NIH, NSF, OAR, SF
Question 5: Services and Supports	5.1	ACL, CDC, DoD-Army, Eagles, ED, ELS, HRSA, NECC, NIH	ACL, AS, CDC, DoD-Army, Eagles, ED, ELS, HRSA, NECC, NIH, PCORI
	5.2	ACL, ASF, AS, Eagles, ED, HRSA, NIH, OAR	ACL, ASF, AS, ED, HRSA, NIH, OAR
	5.3	AHRQ, AS, DoD-Army, ED, HRSA, IMLS, NECC, NIH, NSF, OAR, PCORI	AHRQ, AS, DoD-Army, ED, HRSA, IMLS, NECC, NIH, NSF, OAR, PCORI
Question 6: Lifespan	6.1	ACL, ASF, AS, DoD-Army, Eagles, ED, HRSA, NIH, NJGCA, NSF, OAR, PCORI	ACL, AS, DoD-Army, Eagles, ED, HRSA, NIH, NJGCA, NSF, OAR, PCORI, SSA
	6.2	AS, DoD-Army, NIH, OAR, PCORI, Thrasher	ASF, AS, DoD-Army, ELS, HRSA, NIH, PCORI, Thrasher
	6.3	ACL, AS, DoD-Army, NECC, NIH, NSF, OAR, SSA	ACL, AS, DoD-Army, Eagles, ED, HRSA, NECC, NIH, NSF, SSA
Question 7: Infrastructure and Prevalence	7.1	AS, NIH, SF	AS, NIH, SF
	7.2	ASF, HRSA, NIH, PCORI, SF	ASF, AS, HRSA, NIH, SF
	7.3	AS, ED, HRSA, NIH, NJGCA, NSF, SF	AS, ED, HRSA, NIH, NJGCA, NSF, SF
	7.4	CDC	CDC
Cross-Cutting	Autism in Girls and Women	ASF, AS, BBRF, DoD-Army, Eagles, HRSA, NIH, SF	ASF, AS, BBRF, Eagles, NIH, SF
	Disparities	ACL, ASF, AS, DoD-Army, Eagles, ED, ELS, HRSA, NIH, NSF, OAR, PCORI, SF	ACL, ASF, AS, DoD-Army, ED, ELS, HRSA, NIH, NSF, OAR, PCORI, SF

Table 9. In 2019 and 2020, federal and private funders provided support for each Objective listed in the *2016-2017 IACC Strategic Plan* and funded projects focused on reducing disparities for the autism community. See **Figure 1** for the full text of all Objectives and the Cross-Cutting Theme.

The following sections provide an overview of 2019 and 2020 funding that addresses research Objectives of the *2016-2017 IACC Strategic Plan,* analysis of research Subcategories for each Question, and analyses of each Question's funding over time.

Question 1:
SCREENING AND DIAGNOSIS

ASPIRATIONAL GOAL: Provide the earliest possible diagnosis for people on the autism spectrum, so they can be linked to appropriate interventions, services, and supports in as timely a manner as possible to maximize positive outcomes.

RESEARCH FOCUS OF QUESTION 1

Question 1[3] of the IACC Strategic Plan ("How can I recognize the signs of autism, and why is early detection so important?") pertains to the issues surrounding screening for and diagnosis of autism, with a focus on early identification so that children will have the opportunity to receive interventions and supports that can lead to improved outcomes. The Objectives within this Question of the Strategic Plan include research to develop and improve biomarkers, screening tools, and diagnostic instruments to aid in early identification

of autism. Question 1 topics also include research to reduce disparities in early detection, including efforts to increase access to diagnostic services, and strengthen the evidence base for the benefits of early detection of autism. In addition, the Committee prioritized the need for screening and diagnostic tools for use in adolescents and adults. Projects addressing issues related to adult screening and diagnosis are captured within Question 6 of the Strategic Plan (focused on issues relevant to transition-age youth and adults on the autism spectrum).

---

3 To visually depict the different types of research funded in 2019 and 2020 in each Question area, word clouds were created using the project titles listed under each Question. These appear at the start of each Question's section in the report. The size of the word within the word cloud indicates the frequency of its use in the project titles. The word clouds visually portray the main research themes and topics that were associated with the projects categorized under each Question.

ANALYSIS OF 2019-2020 QUESTION 1 PORTFOLIO

When analyzing the distribution of research dollars across the seven Question areas of the IACC Strategic Plan, projects assigned to Question 1 comprised 5.4% ($22.9 million) of total autism research funding in 2019 and 7.1% ($29.9 million) of funding in 2020. A total of 91 projects were assigned to Question 1 in 2019, which was 5.7% of all projects. In 2020, 105 projects were aligned to Question 1, representing 6.7% of all projects. The largest funders of research pertaining to Question 1 in 2019 and 2020 were the National Institutes of Health and the Simons Foundation. Question 1 includes three Objectives. **Figures 25** and **26** provide a detailed overview of each Objective's funding in 2019 and 2020 as well as the number of projects assigned to each Objective.

In 2019 and 2020, all three Question 1 Objectives were in progress and received funding. The Question 1 Objective that received the most funding was **Objective 1.3**, which aims to improve and develop new tools and service models for detecting autism; it received 79.9% ($18.3 million) of the Question 1 funding in 2019 and 81.1% ($24.2 million) in 2020. Objective 1.3 had the largest number of the Question 1 projects; this corresponds to 75 projects in 2019 and 89 projects in 2020. This was followed by **Objective 1.1**, which

focuses on strengthening the evidence base for the benefits of early detection of autism. In 2019, Objective 1.1 accounted for 11.3% ($2.6 million) of Question 1 funding and included six projects. In 2020, Objective 1.1 accounted for 14.6% ($4.4 million) of Question 1 funding and also included six projects. **Objective 1.2** received 4.5% ($1.0 million) of Question 1 funding in 2019 and had seven projects. The goal of this Objective is to reduce disparities in early detection and access to services. In 2020, Objective 1.2 accounted for 1.5% ($436,679) of Question 1 funding and included eight projects. Three projects were categorized as Core/Other (i.e., projects not specific to Question 1 Objectives) in 2019 (4.3%; $995,185), and 2020 included two projects categorized as Core/Other (2.8%; $848,332). These included a project investigating the etiologies of "complex" versus "essential" autism, a project focused on the neuroethics of and parental attitudes toward predictive magnetic resonance imaging (MRI) testing to identify autism before characteristics manifest, a project to determine positron emission tomography (PET) imaging dosage using artificial neural networks, and a project that examines preverbal social learning in minimally verbal children with autism.

2019
Question 1: Screening and Diagnosis
Total Funding: $22,878,014
Number of Projects: 91

Objective

6	1.1	$2,587,942
7	1.2	$1,023,262
75	1.3	$18,271,626
3	1.0	$995,185

Number of Projects   Funding Amount (millions)
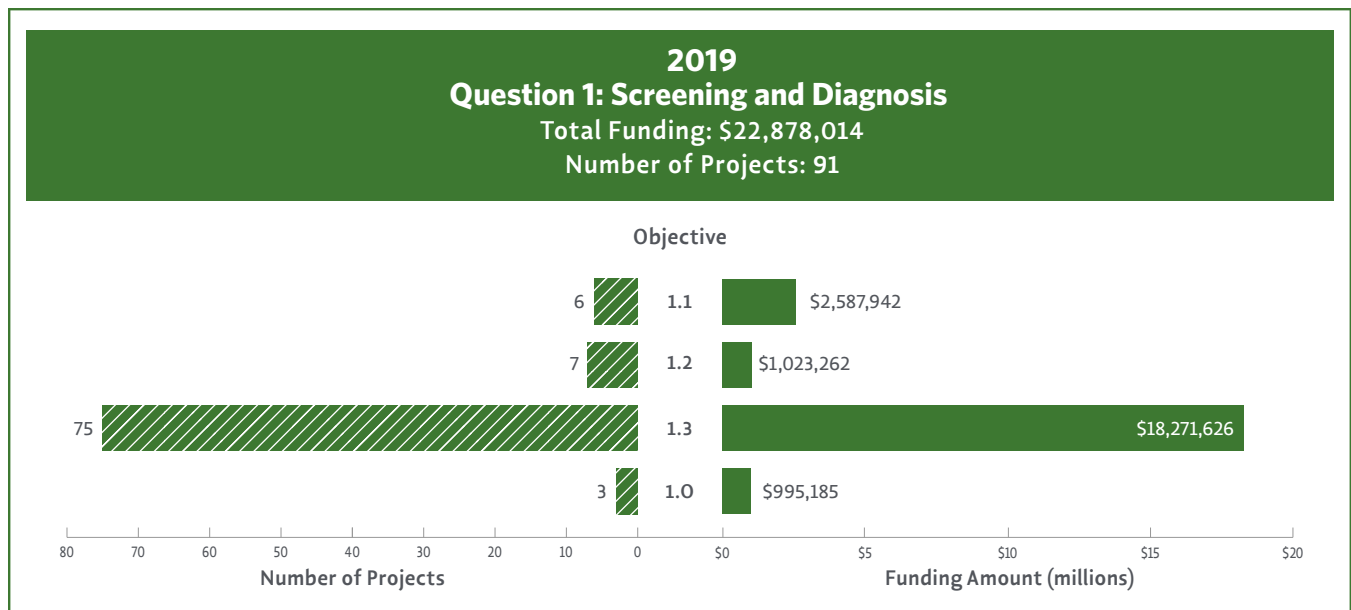
Figure 25. 2019 funding and number of projects for Question 1 Objectives. 1.1: Strengthen the evidence base for the benefits of early detection of autism; 1.2: Reduce disparities in early detection and access to services; 1.3: Improve/validate existing or develop new tools, methods, and service delivery models for detecting autism in order to facilitate timely linkage of individuals with autism to early, targeted interventions and supports; 1.O: Projects that do not align with Question 1 Objectives or support "core" activities in the autism research field were labeled "Core/Other."

2020
Question 1: Screening and Diagnosis
Total Funding: $29,896,564
Number of Projects: 105

Objective

6	1.1	$4,372,262
8	1.2	$436,679
89	1.3	$24,239,291
2	1.0	$848,332

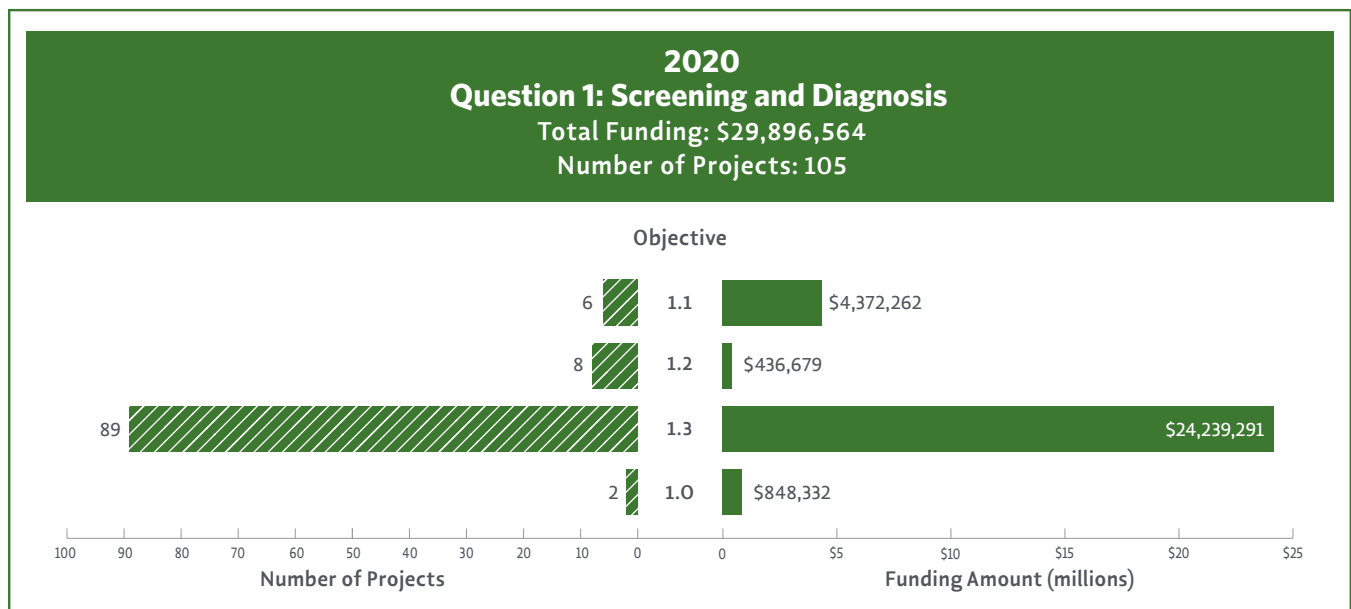Number of Projects   Funding Amount (millions)

Figure 26. 2020 funding and number of projects for Question 1 Objectives. See Figure 25 caption for descriptions of each Objective.

QUESTION 1 SUBCATEGORY ANALYSIS

All 2019 and 2020 autism projects were categorized into "Subcategories," which are broad research topics or themes. Even if a project did not fit within a particular Objective of the Strategic Plan, it was still assigned to a specific Subcategory. This enables a comprehensive understanding of the distribution of all projects across the research topics aligned with each Question area. Overall, projects in Question 1 were divided into four Subcategories: Diagnostic and Screening Tools; Early Signs and Biomarkers; Phenotypes/Subgroups; and Spectrum of Characteristics (**Figures 27** and **28**).

Of these four Subcategories, the largest proportion of 2019 and 2020 funding was devoted to **Diagnostic and Screening Tools** for autism (58.6% in 2019; 49.6% in 2020); this included 49 projects in 2019 and 50 projects in 2020. Identifying **Early Signs and Biomarkers** was the second largest research investment in Question 1 (33.0%, 33 projects in 2019; 30.1%, 41 projects in

2020). Included in this Subcategory were biological indicators (including genetic, metabolic, and brain structure/connectivity) and behavioral biomarkers that can be used for screening/diagnosis or to measure response to interventions. Projects assigned to **Spectrum of Characteristics** received the next largest proportion of funding for Question 1 (5.0%, 7 projects in 2019; 12.7%, 9 projects in 2020). This Subcategory captures projects that seek to define the broad range of autism characteristics, including variations in neurocognitive development and differences in social communication, language, cognitive ability, sensory sensitivities, and executive functioning ability. Identifying **Phenotypes/Subgroups** of people with autism received 3.5% of Question 1 funding in 2019, accounting for two projects, and 7.7% of Question 1 funding in 2020 with five projects.

2019
Question 1: Screening and Diagnosis
Funding by Subcategory

Spectrum of Characteristics
$1,139,790
5.0 %
7 projects

Phenotypes/Subgroups
$792,244
3.5%
2 projects

Diagnostic and Screening Tools
$13,401,987
58.6%
49 projects

Early Signs and Biomarkers
$7,543,994
33.0%
33 projects
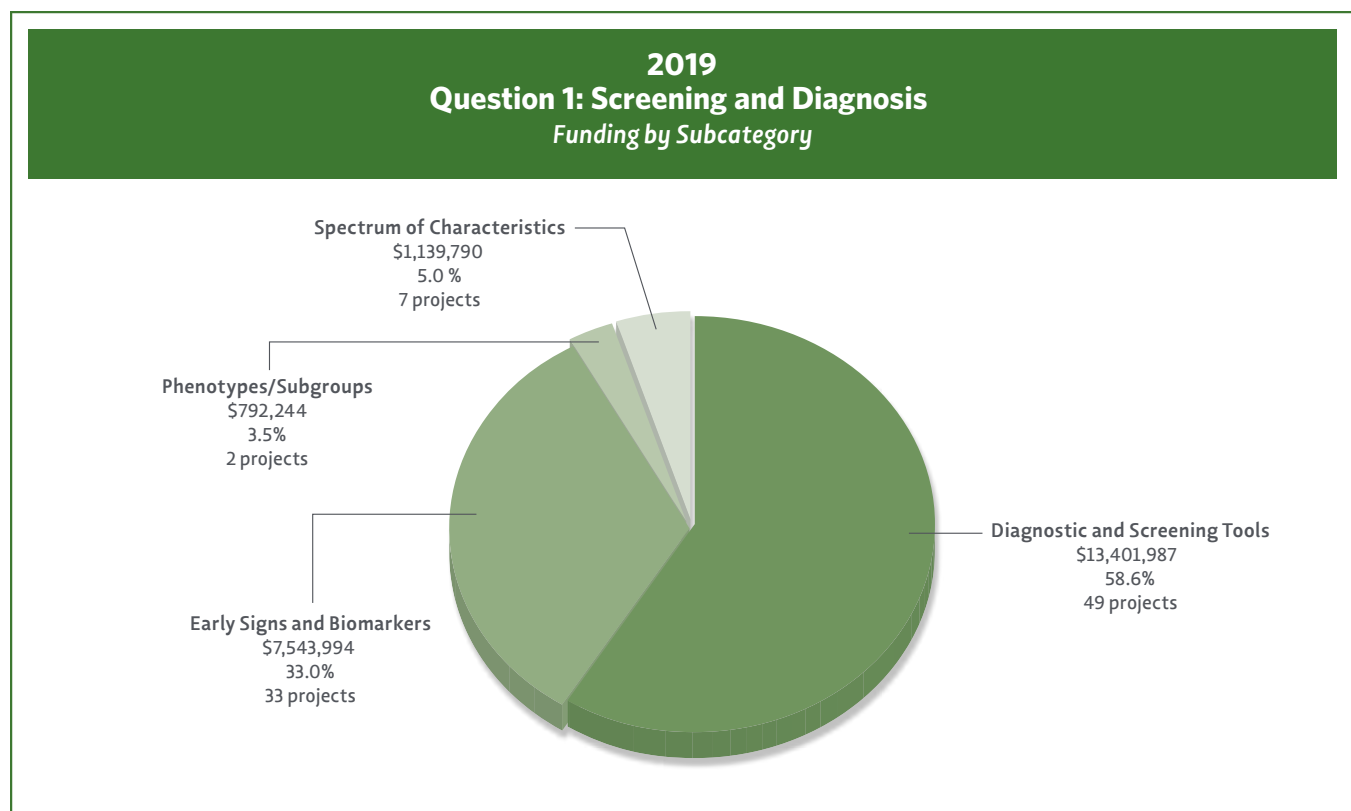
Figure 27. 2019 Question 1 funding by Subcategory.
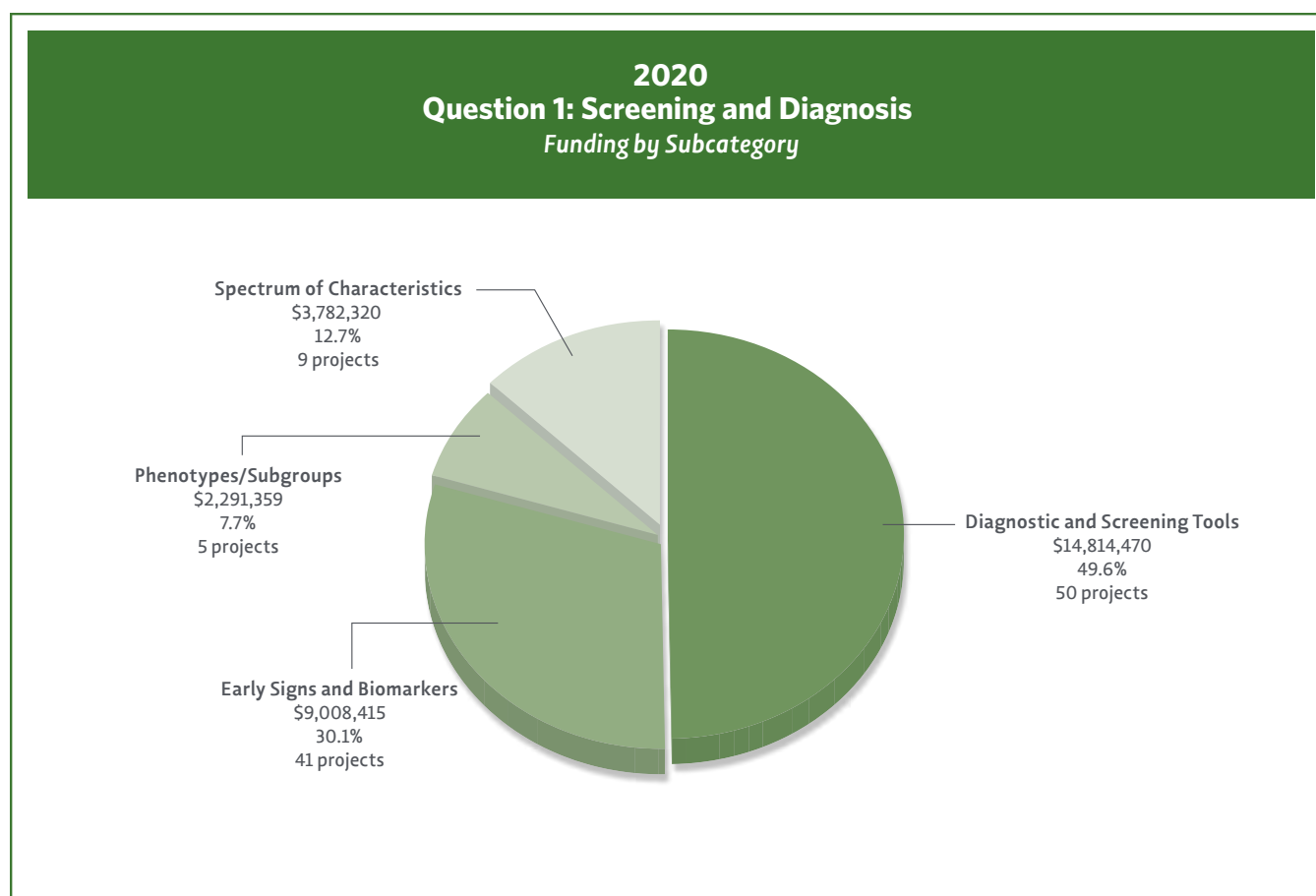
Figure 28. 2020 Question 1 funding by Subcategory.

QUESTION 1 FUNDING OVER TIME: 2008-2020

Figure 29 shows the trend in Question 1 funding over time. When considering annual funding for Question 1 from 2008-2019, portfolio analysis data show that funding levels stayed relatively flat since 2008, with the exception of 2009 and 2010, during which federal funding for autism research increased due to the ARRA.

Question 1 saw a recent relative increase in 2020 with the inclusion of new National Institutes of Health-funded projects aimed at addressing **U.S. Preventive Services Task Force (USPSTF) recommendations** on early autism screening and diagnosis.
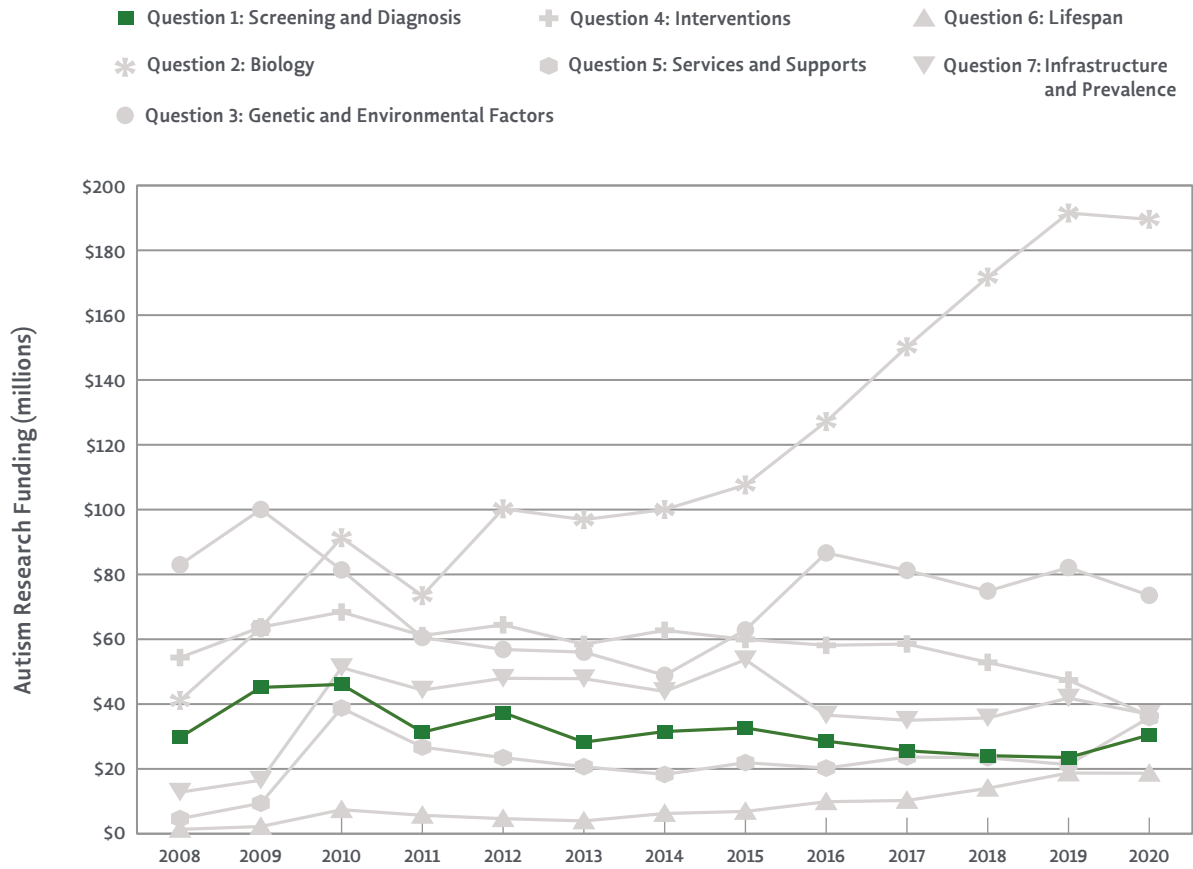
Figure 29. Question 1 autism research funding from 2008-2020. Funding for Question 1 saw an increase in 2009 and 2010 due to ARRA funding. Since 2011, Question 1 funding has been moderate and relatively flat, with a recent relative increase in 2020.

Question 2:
BIOLOGY

ASPIRATIONAL GOAL: Discover how alterations in brain development and the function of physiological systems lead to autism in order to enable the development of effective, targeted interventions and societal accommodations that improve quality of life for people on the autism spectrum.

RESEARCH FOCUS OF QUESTION 2

Question 2 ("What is the biology underlying autism?") seeks to understand the biological differences and mechanisms in early development and throughout life that contribute to autism features, as well as characterization of the behavioral and cognitive aspects of autism. The aim of the research represented by Question 2 is to understand the biological processes underlying autism from the molecular level to sensory, motor, behavioral, cognitive, and physiological development and functioning. Projects range from basic neuroscience using cellular and animal models to clinical studies. In addition, Question 2 addresses physical and mental health conditions that co-occur with autism.

ANALYSIS OF 2019-2020 QUESTION 2 PORTFOLIO

Among the seven Question areas described in the IACC Strategic Plan, Question 2 accounted for the largest portion of the autism research portfolio in 2019 and 2020. Research on the Biology of autism (Question 2) comprised 45.3% of total funding in 2019 ($192.3 million) and 45.4% of funding in 2020

($190.3 million). Question 2 also had the largest portion of overall projects in 2019 (38.6%, 619 projects) and 2020 (37.5%, 590 projects). Among federal agencies and private organizations, the National Institutes of Health and the Simons Foundation provided the largest investments for Question 2 funding in 2019 and 2020. Research projects in Question 2 are categorized under three Objectives. **Figures 30** and **31** provide an overview of each Objective's funding in 2019 and 2020 as well as the number of projects belonging to each Objective.

All three Objectives in Question 2 were in progress and received funding in 2019 and 2020. **Objective 2.1** had the most projects, with 75.4% of Question 2 funding ($145.1 million) in 2019 and 81.5% ($155.1 million) in 2020. Projects aligned to Objective 2.1 included 518 projects in 2019 and 505 projects in 2020. The aim of this Objective is to better understand the biological, molecular, and brain processes that contribute to autism. The next largest portion of funding went to **Objective 2.3**, which focuses on supporting large-scale

longitudinal studies of autism that assess the natural lifespan. Objective 2.3 was 10.9% of Question 2 funding in 2019 and 11.1% in 2020 ($21.0 million in 2019 and $21.1 million in 2020) and totaled 36 projects and 34 projects, respectively. **Objective 2.2**, which emphasizes research on understanding co-occurring physical and mental health conditions, received $20.3 million and accounted for 10.5% of Question 2 funding in 2019 (46 projects). In 2020, Objective 2.2 had 6.9% of Question 2 funding ($13.1 million) and included 43 projects.

In 2019, 3.1% of Question 2 funding was assigned to Core/Other ($6.0 million, 19 projects). Less than 1% ($948,658; 8 projects) of Question 2 funding was assigned to Core/Other in 2020. Projects assigned to Core/Other included research studying the effects of environmental exposures on the development of the infant gut microbiome and the behavioral effects of fever on young children with autism, as well as support for statistical analyses of large data sets.

2019
Question 2: Biology
Total Funding: $192,267,350
Number of Projects: 619

Objective		
518	2.1	$145,050,853
46	2.2	$20,270,300
36	2.3	$20,996,091
19	2.0	$5,950,106

Number of Projects — Funding Amount (millions)
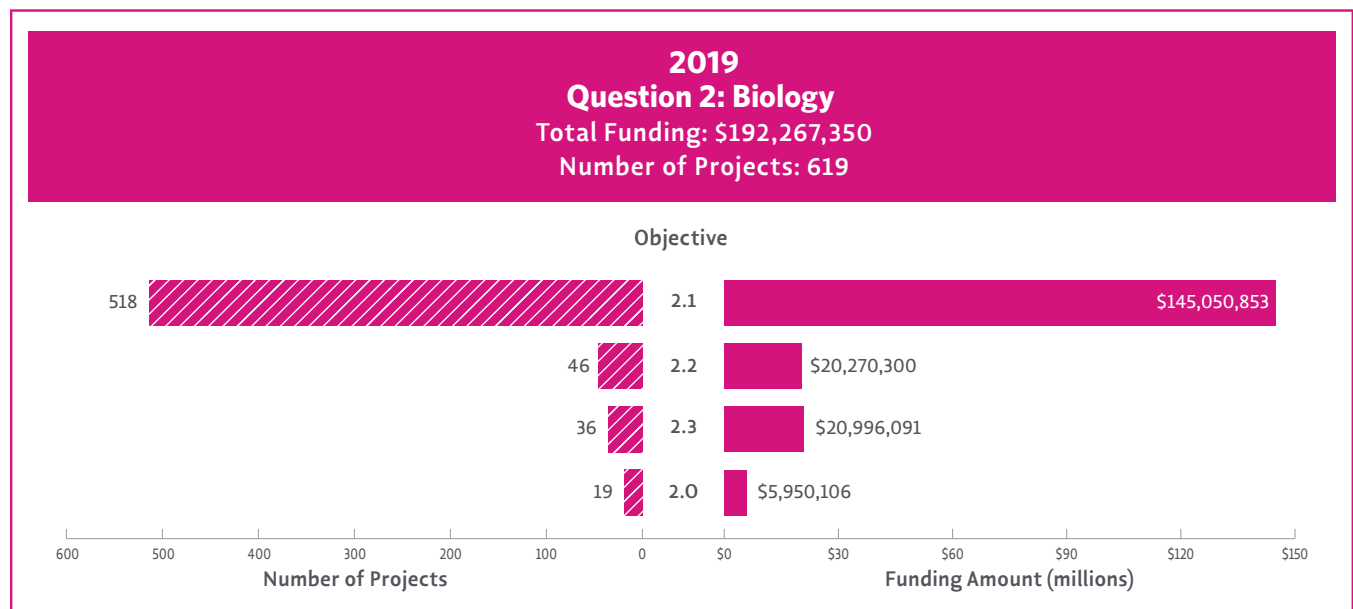
Figure 30. 2019 funding and number of projects for Question 2 Objectives. 2.1: Foster research to better understand the processes of early development, molecular and neurodevelopmental mechanisms, and brain circuitry that contribute to the structural and functional basis of autism; 2.2: Support research to understand the underlying biology of co-occurring conditions in autism and to understand the relationship of these conditions to autism; 2.3: Support large-scale longitudinal studies that can answer questions about the development of autism from pregnancy through adulthood and the natural history of autism across the lifespan; 2.O: Projects that do not align with Question 2 Objectives or support "core" activities in the autism research field were labeled "Core/Other."

2020
Question 2: Biology
Total Funding: $190,289,259
Number of Projects: 590

Objective

Number of Projects	Objective	Funding Amount
505	2.1	$155,128,949
43	2.2	$13,071,782
34	2.3	$21,139,870
8	2.0	$948,658

Number of Projects — Funding Amount (millions)

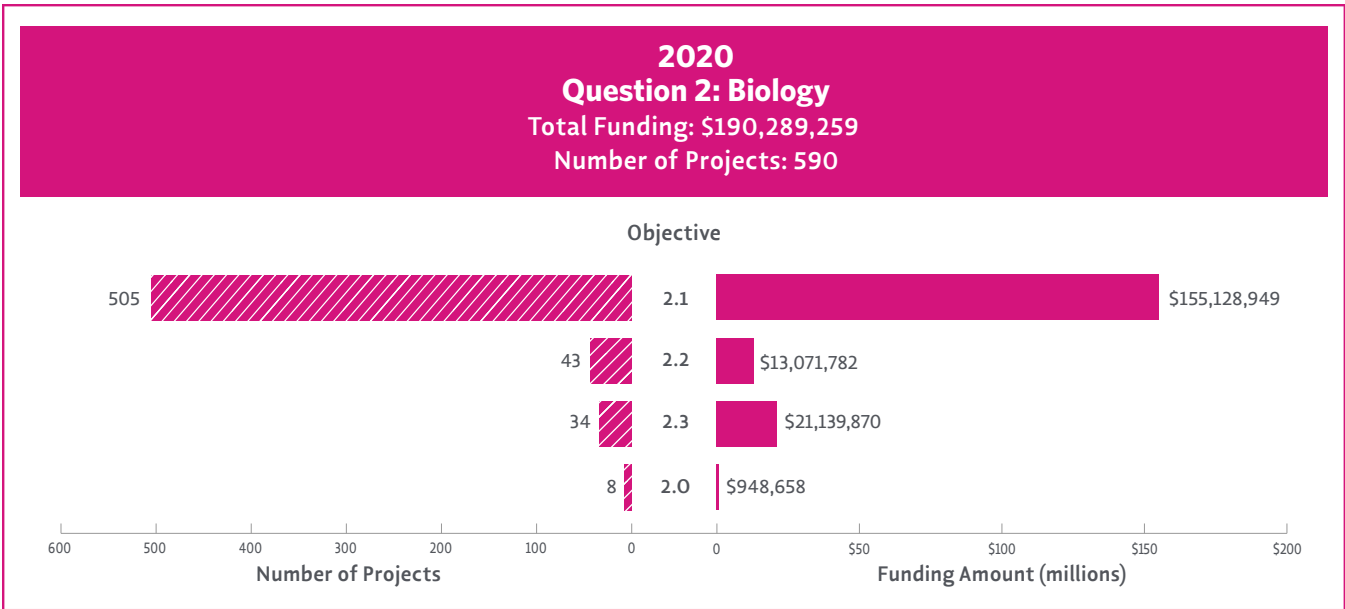**Figure 31.** 2020 funding and number of projects for Question 2 Objectives. See Figure 30 caption for descriptions of each Objective.

QUESTION 2 SUBCATEGORY ANALYSIS

The Subcategory analysis is particularly useful for Question 2 in understanding the distribution of research on the underlying biological mechanisms of autism. Research in this area covers a broad array of scientific fields, and thus Question 2 was divided into several Subcategories. These include Cognitive Studies; Computational Science; Co-Occurring Conditions; Developmental Trajectory; Immune/Metabolic Pathways; Molecular Pathways; Neural Systems; Neuropathology; Sensory and Motor Function; and Subgroups/Biosignatures (**Figures 32** and **33**).

As in previous years, the Question 2 Subcategory with the largest portion of funding in 2019 and 2020 was **Molecular Pathways** (32.6% with 222 projects and 33.5% with 202 projects, respectively), which includes projects seeking to understand how specific genes, proteins, and other molecules interact to influence autism phenotypes. Research exploring **Neural Systems**, such as the structure of the brain

and functional connections within the brain, was the second largest investment in 2019 (15.6%, 91 projects). Research on the **Developmental Trajectory** of autism, including longitudinal studies that follow social, behavioral, and physical development over time, accounted for 11.6% (37 projects) of Question 2 funding in 2019. In 2020, Developmental Trajectory accounted for 15.1% of Question 2 funding (41 projects), and Neural Systems accounted for 14.1% of Question 2 funding (75 projects). In 2019, research on **Co-Occurring Conditions** was the next largest Subcategory and accounted for 8.7% of Question 2 funding (38 projects). For both 2019 and 2020, projects seeking to identify **Subgroups/ Biosignatures** of autism accounted for approximately 8% of Question 2 funding in both years (8.3% and 59 projects in 2019; 7.9% and 46 projects in 2020). **Sensory and Motor Function** accounted for 6.2% (56 projects) and 6.5% (67 projects) of Question 2 funding in 2019 and 2020, respectively, while **Cognitive**

Studies research, which includes studies of language development, learning, and behavior, accounted for 5.8% (39 projects) of 2019 Question 2 funding and 6.1% (46 projects) of 2020 Question 2 funding. In 2020, the Co-Occurring Conditions Subcategory made up 4.7% of Question 2 funding with 37 projects. In 2019, research on **Neuropathology** accounted for 4.4% of Question 2 funding (22 projects), and research in

the areas of **Computational Science** and **Immune/ Metabolic Pathways** accounted for 3.7% (24 projects) and 3.0% (31 projects) of 2019 Question 2 funding, respectively. In 2020, Computational Science made up 4.6% of Question 2 funding (27 projects), and research on Neuropathology and Immune/Metabolic Pathways each accounted for 4.0% (17 projects) and 3.6% (32 projects) of Question 2 funding, respectively.

2019
Question 2: Biology
Funding by Subcategory

Subgroups/Biosignatures
$15,928,925
8.3%
59 projects

Cognitive Studies
$11,121,794
5.8%
39 projects

Computational Science
$7,149,371
3.7%
24 projects

Sensory and Motor Function
$11,992,418
6.2%
56 projects

Co-Occurring Conditions
$16,775,420
8.7%
38 projects

Neuropathology
$8,487,655
4.4%
22 projects

Developmental Trajectory
$22,284,828
11.6%
37 projects

Neural Systems
$29,917,580
15.6%
91 projects

Immune/Metabolic Pathways
$5,860,211
3.0%
31 projects

Molecular Pathways
$62,749,150
32.6%
222 projects

Figure 32. 2019 Question 2 funding by Subcategory.

2020
Question 2: Biology
Funding by Subcategory

Subgroups/Biosignatures
$15,099,450
7.9%
46 projects

Cognitive Studies
$11,614,226
6.1%
46 projects

Computational Science
$8,686,857
4.6%
27 projects

Sensory and Motor Function
$12,312,471
6.5%
67 projects

Co-Occurring Conditions
$8,956,786
4.7%
37 projects

Neuropathology
$7,538,819
4.0%
17 projects

Developmental Trajectory
$28,750,164
15.1%
41 projects

Neural Systems
$26,779,792
14.1%
75 projects

Immune/Metabolic Pathways
$6,882,033
3.6%
32 projects

Molecular Pathways
$63,668,663
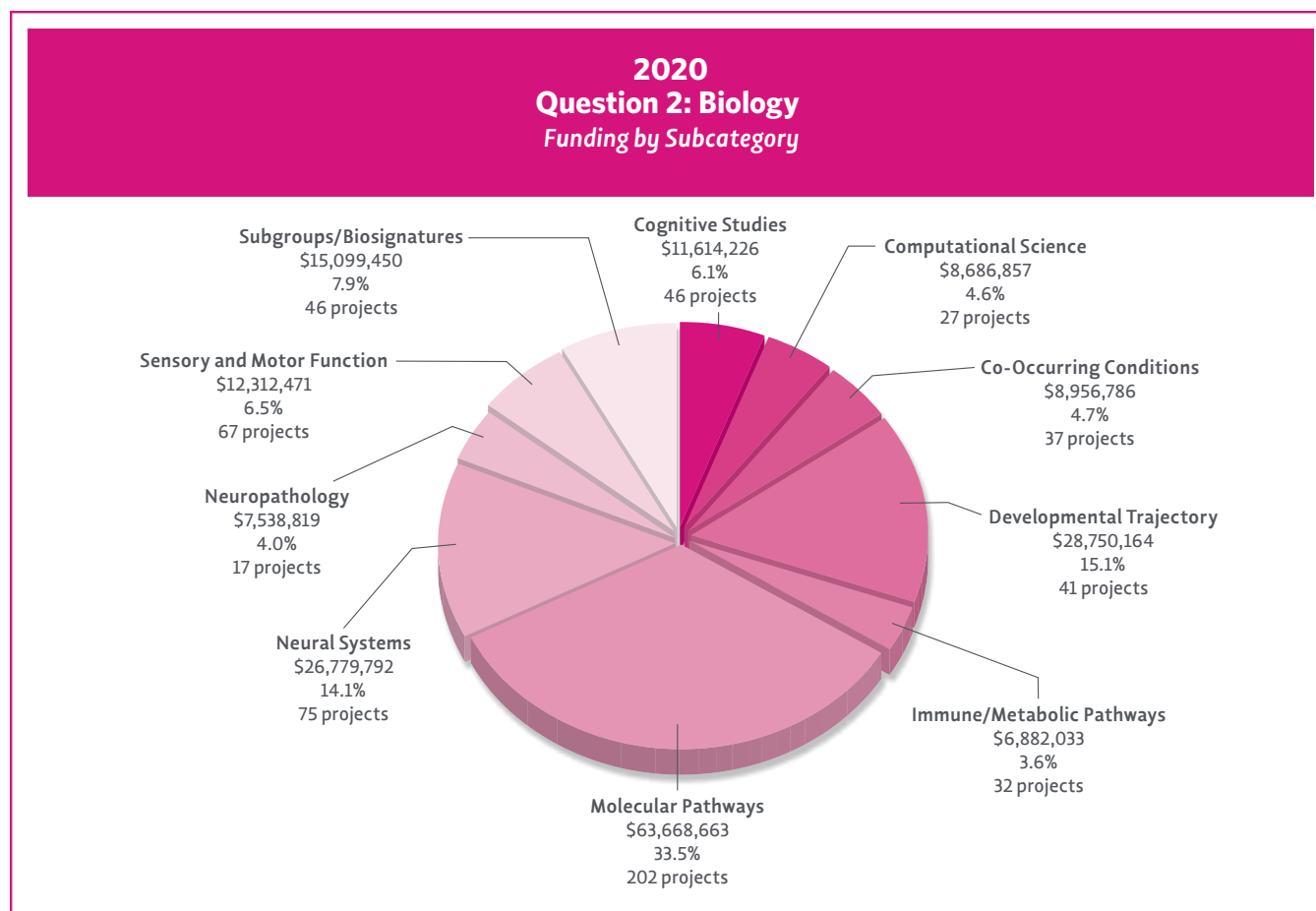33.5%
202 projects

Figure 33. 2020 Question 2 funding by Subcategory.

QUESTION 2 FUNDING OVER TIME: 2008-2020

Figure 34 shows the trend in funding for Question 2 over time. Overall, funding for projects within Question 2 was higher than those of other Question areas. When considering annual funding for Question 2 from 2008-2020, funding has increased significantly in recent years, with the exception of a slight decrease in 2020. It is important to note that in 2016, the formulation of the *2016-2017 Strategic Plan* Objectives led to the

reassignment of some projects from Question 4 to Question 2 based on the goals of the new Objectives. This contributed in part to the overall pattern of growth illustrated in **Figure 34**. Nevertheless, Question 2 is the area that has seen the most sustained and consistent growth over all the years of the IACC's portfolio analysis.
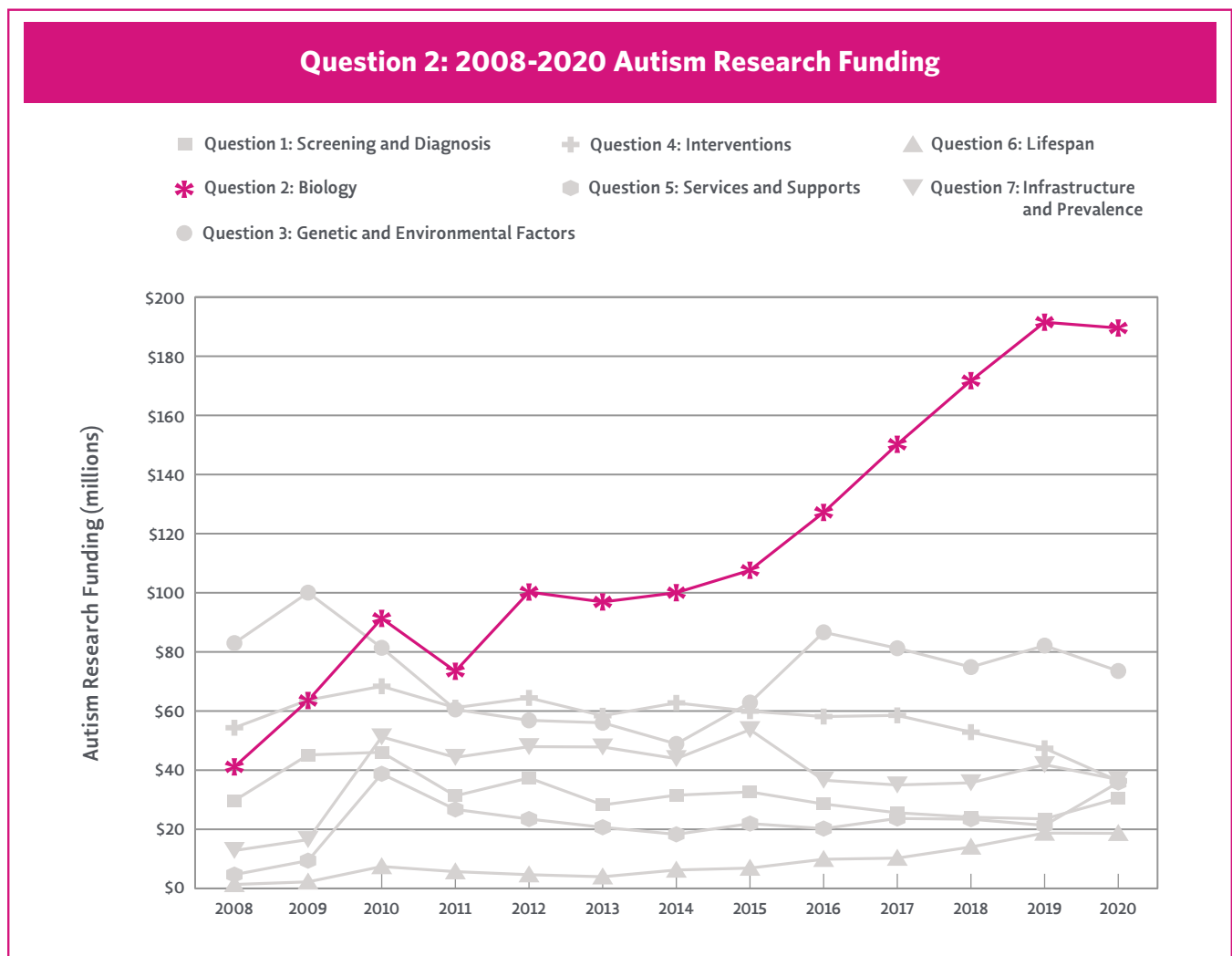

Figure 34. Question 2 autism research funding from 2008-2020. Funding for Question 2 has experienced several increases in funding over the 13-year span.

Question 3:
GENETIC AND ENVIRONMENTAL FACTORS

ASPIRATIONAL GOAL: Causes of autism will be discovered that inform diagnosis, prognosis, and interventions and lead to prevention or preemption of the challenges and disabilities of autism.

RESEARCH FOCUS OF QUESTION 3

Question 3 ("What causes autism, and can disabling aspects of autism be prevented or preempted?") focuses on the genetic and environmental factors associated with the development of autism. Research related to Question 3 explores the role of genetics, epigenetics, and the environment in the development of autism, as well as the interactions between these factors. Question 3 Objectives address topics such as the role of genetics through whole-genome sequencing and the relationship with clinical outcomes. Also included is research to develop improved approaches to study environmental exposures and gene-environment interactions.

ANALYSIS OF 2019-2020 QUESTION 3 PORTFOLIO

In 2019, research on Genetic and Environmental Factors associated with autism (Question 3) accounted for $82.0 million (19.3%) of total autism research funding. A total of 233 projects were assigned to Question 3, which was 14.5% of all projects in the 2019 autism portfolio. In 2020, Question 3 received 17.5% ($73.3 million) of the portfolio's funding and included 224 projects (14.2% of total projects). The largest funders of Question 3 during this period were the National Institutes of Health, Simons Foundation, and the Centers for Disease Control and Prevention. Question 3 consists of three Objectives. **Figures 35** and **36** provide a detailed overview of each Objective's funding in 2019 and 2020 as well as the number of projects assigned to each Objective.

Each Question 3 Objective was in progress and received funding in 2019 and 2020. **Objective 3.1**, which identifies and strengthens the understanding of genetic factors that play a role in the development of autism, received the largest proportion of funding in 2019 at 47.7% ($39.1 million) and included 143 projects.

This was followed by **Objective 3.3**, which supports projects studying the interaction of environmental exposures and genetic factors. Objective 3.3 accounted for 43.4% of Question 3 funding ($35.6 million) and 63 projects in 2019. In 2020, Objective 3.3 and Objective 3.1 received 44.9% ($32.9 million) and 44.7% ($32.7 million) of Question 3 funding, accounting for 57 and 140 projects, respectively. **Objective 3.2**, focused on environmental factors associated with autism, received the least amount of funding for both 2019 and 2020. In 2019, Objective 3.2 received $7.3 million, accounting for 8.9% of Question 3 funding and 27 projects. In 2020, Objective 3.2 projects totaled $7.5 million and was 10.2% of Question 3 funding (26 projects). Question 3 did not include any projects under the Core/Other category in 2019. One 2020 Question 3 project was categorized as Core/Other ($172,734; <1%), which used prairie voles as a model to investigate how delivery by caesarean section may impact changes in social behavior related to autism.
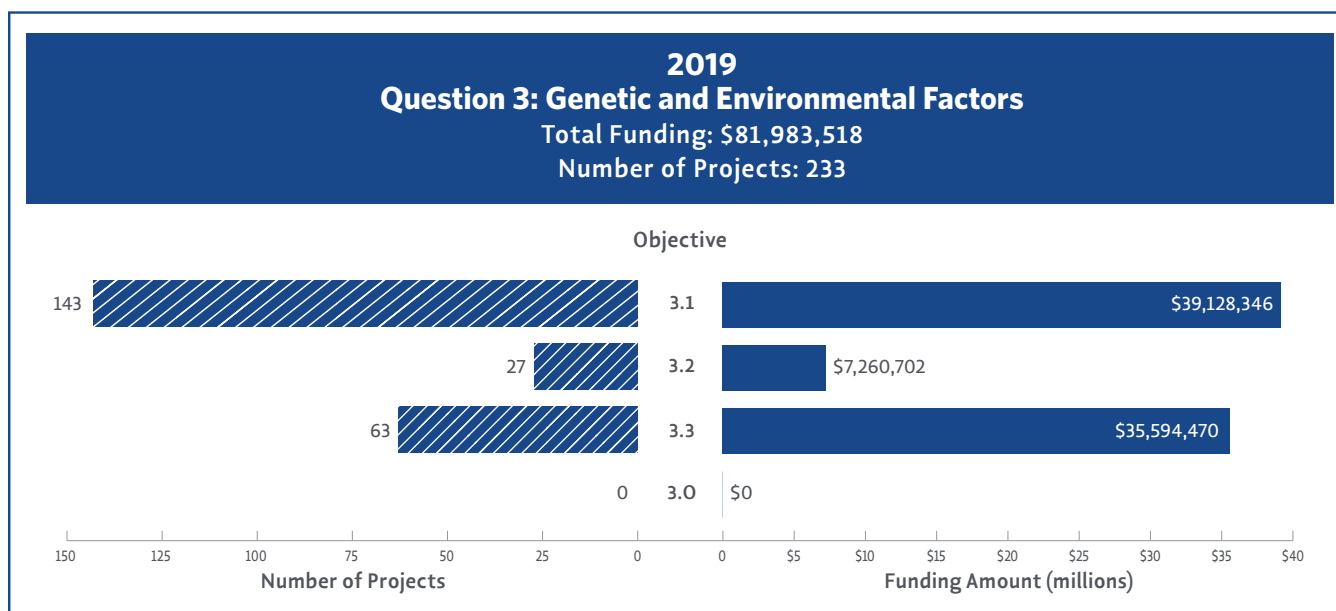
2019
Question 3: Genetic and Environmental Factors
Total Funding: $81,983,518
Number of Projects: 233

Objective

Number of Projects	Objective	Funding Amount (millions)
143	3.1	$39,128,346
27	3.2	$7,260,702
63	3.3	$35,594,470
0	3.0	$0

Figure 35. 2019 funding and number of projects for Question 3 Objectives. 3.1: Strengthen understanding of genetic factors for autism across the full diversity and heterogeneity of those with autism, enabling development of strategies for reducing disability and co-occurring conditions in autism; 3.2: Understand the effects on autism of individual and multiple exposures in early development, enabling development of strategies for reducing disability and co-occurring conditions in autism; 3.3: Expand knowledge about how multiple environmental and genetic factors interact through specific biological mechanisms to manifest in autism phenotypes; 3.O: Projects that do not align with Question 3 Objectives or support "core" activities in the autism research field were labeled "Core/Other."
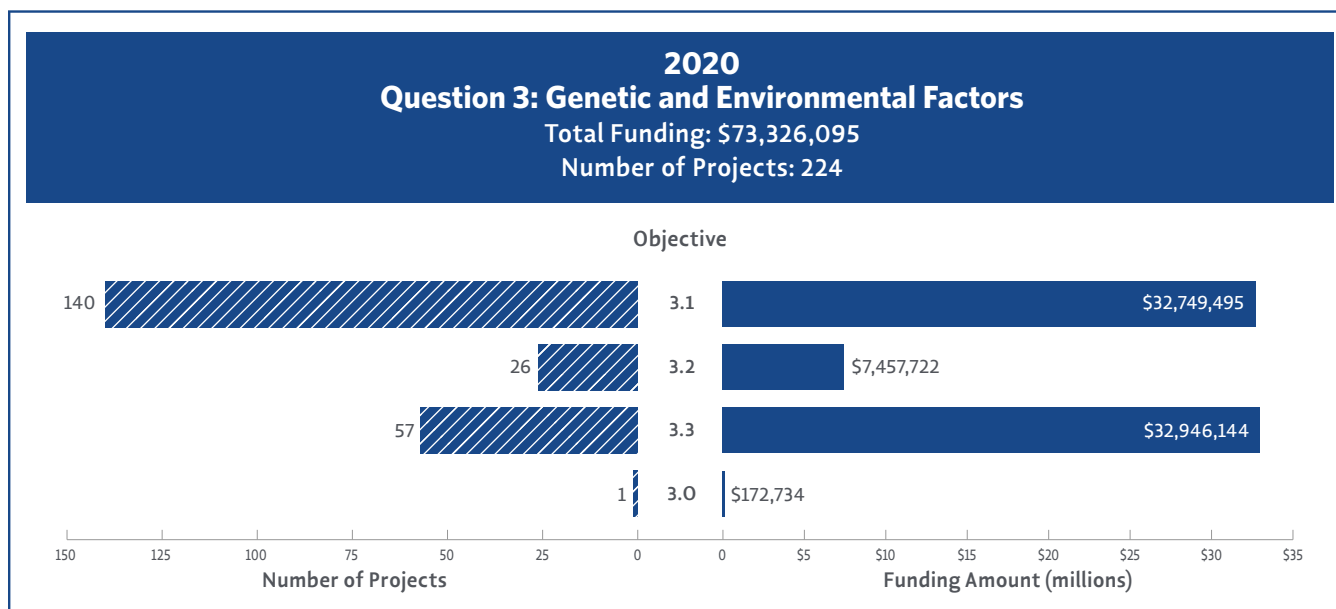
2020
Question 3: Genetic and Environmental Factors
Total Funding: $73,326,095
Number of Projects: 224

Objective

Number of Projects	Objective	Funding Amount (millions)
140	3.1	$32,749,495
26	3.2	$7,457,722
57	3.3	$32,946,144
1	3.0	$172,734

Figure 36. 2020 funding and number of projects for Question 3 Objectives. See Figure 35 caption for description of each Objective.

QUESTION 3 SUBCATEGORY ANALYSIS

Projects in Question 3 were divided into four Subcategories to determine the funding distribution across research areas related to understanding and identifying genetic and environmental factors of autism. These Subcategories include Environmental Factors; Epigenetics; Gene-Environment studies; and Genetic Factors (**Figures 37** and **38**).

For both years of the portfolio analysis, studies focused on **Genetic Factors** accounted for the highest percentage of Question 3 funding (2019: 47.7%, 143 projects; 2020: 44.7%, 140 projects). The next largest Question 3 Subcategory investigates the interaction of environmental factors, genetic susceptibility, and/or the context of human physiology (**Gene-Environment**); this Subcategory received 22.2% of Question 3 funding and included 37 projects in 2019 and 27.0% of funding and 38 projects in 2020. Projects on **Epigenetics** received 21.3% of funding (25 projects) in 2019 and 17.9% of funding (19 projects) in 2020; these included studies investigating DNA modifications due to environmental and physiological influences. Projects considering solely **Environmental Factors** received 8.9% of Question 3 funding in 2019 (28 projects). In 2020, this Subcategory accounted for 10.4% of Question 3 funding and had 27 projects.
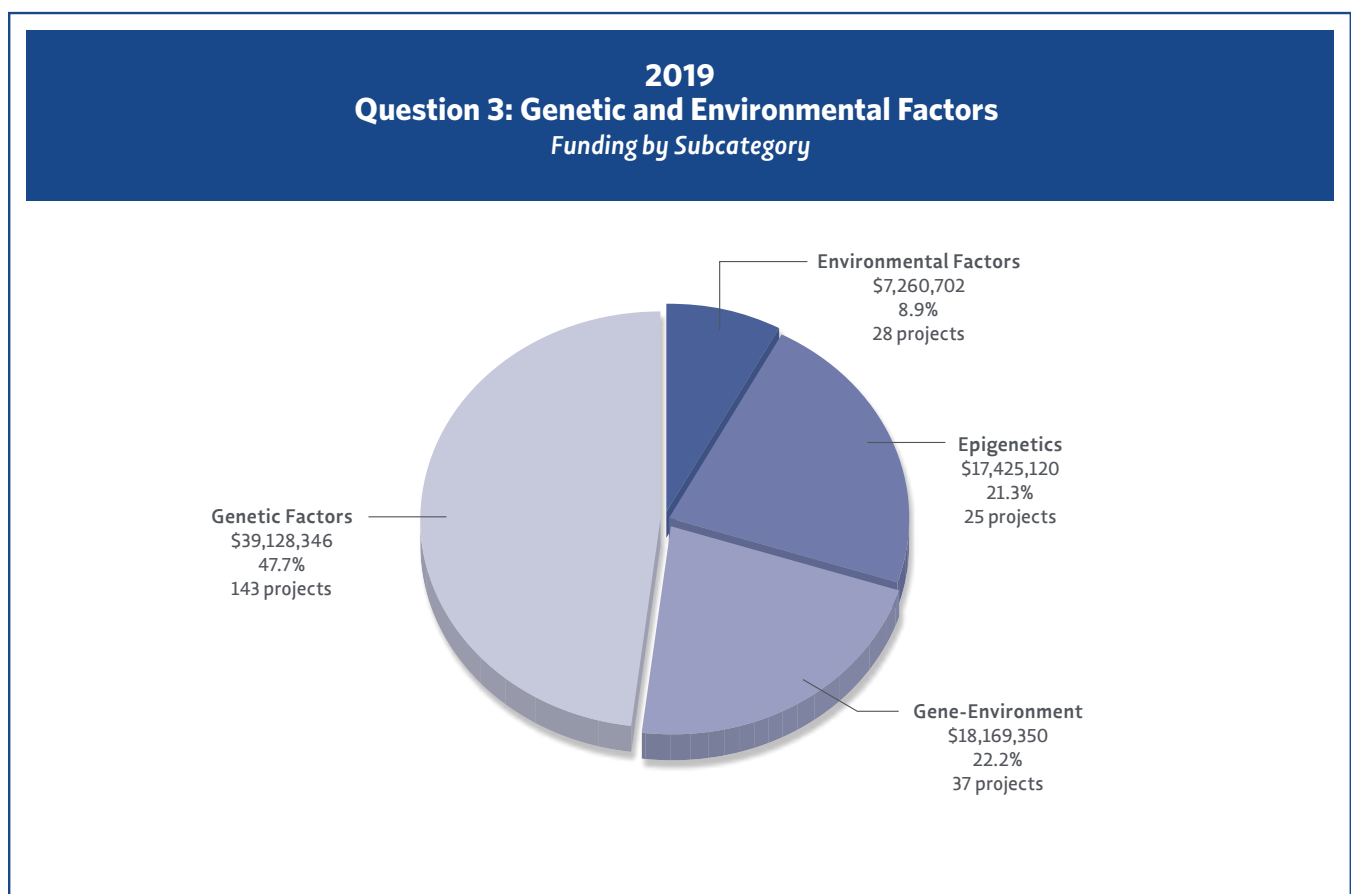

2019
Question 3: Genetic and Environmental Factors
Funding by Subcategory

Environmental Factors
$7,260,702
8.9%
28 projects

Epigenetics
$17,425,120
21.3%
25 projects

Genetic Factors
$39,128,346
47.7%
143 projects

Gene-Environment
$18,169,350
22.2%
37 projects

Figure 37. 2019 Question 3 funding by Subcategory.

2020
Question 3: Genetic and Environmental Factors
Funding by Subcategory

Environmental Factors
$7,630,456
10.4%
27 projects

Epigenetics
$13,112,869
17.9%
19 projects

Genetic Factors
$32,749,495
44.7%
140 projects

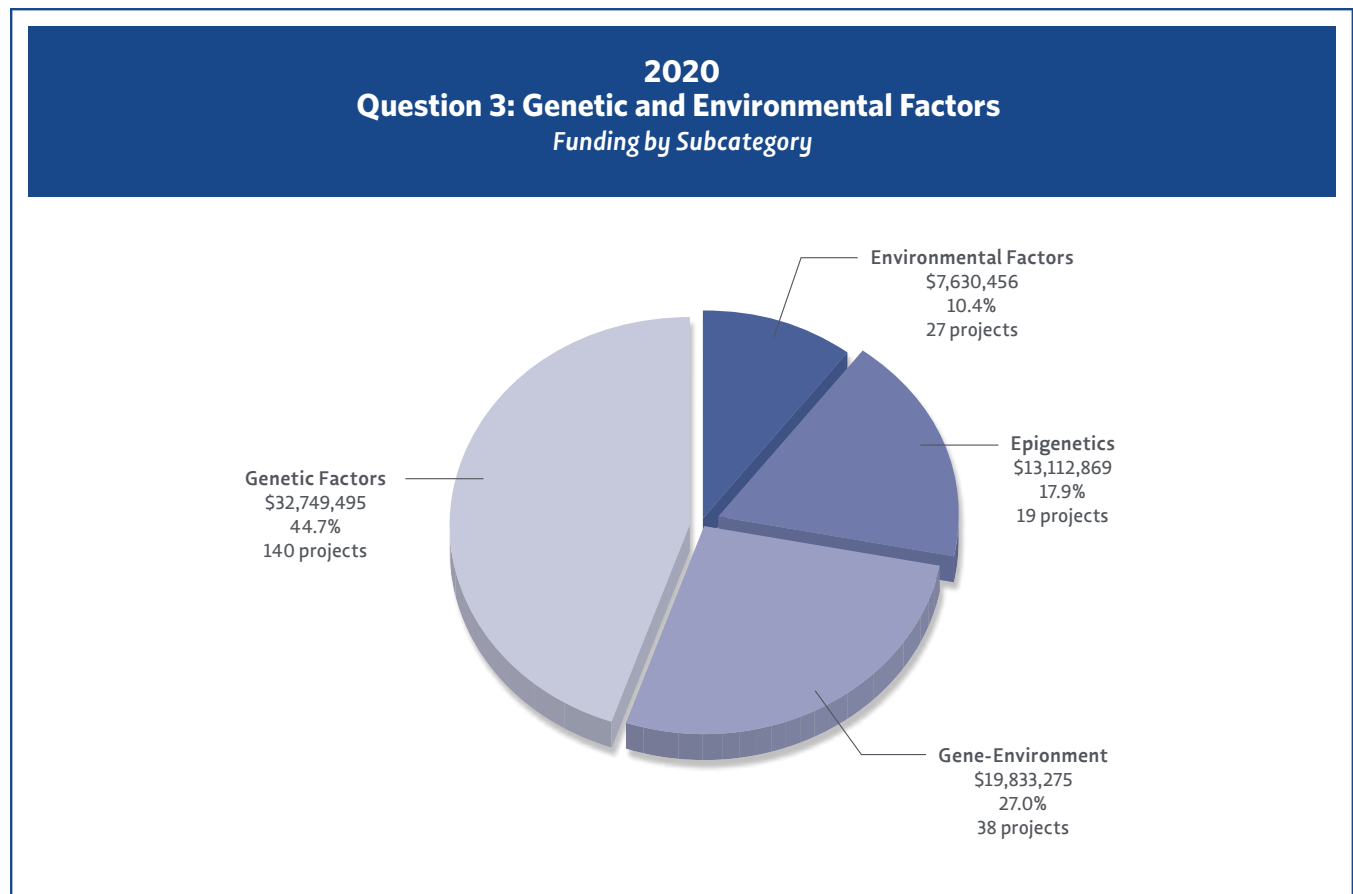Gene-Environment
$19,833,275
27.0%
38 projects

Figure 38. 2020 Question 3 funding by Subcategory.

QUESTION 3 FUNDING OVER TIME: 2008-2020

Figure 39 shows Question 3 funding over time. While research on Genetic and Environmental Factors has been funded at high levels over the 13-year period compared to some of the other areas, Question 3 has experienced several fluctuations in funding throughout the years. The overall trend showed an initial increase in funding followed by a significant decrease and then smaller decreases in funding from 2011 to 2014. Between 2014 and 2016 there was a 78.6% increase in funding for Question 3. The increase in 2016 was due in part to reassignment of SPARK genetics projects to a new Objective within Question 3 that was added in the *2016-2017 IACC Strategic Plan*. Question 3 funding has since modestly decreased in recent years.
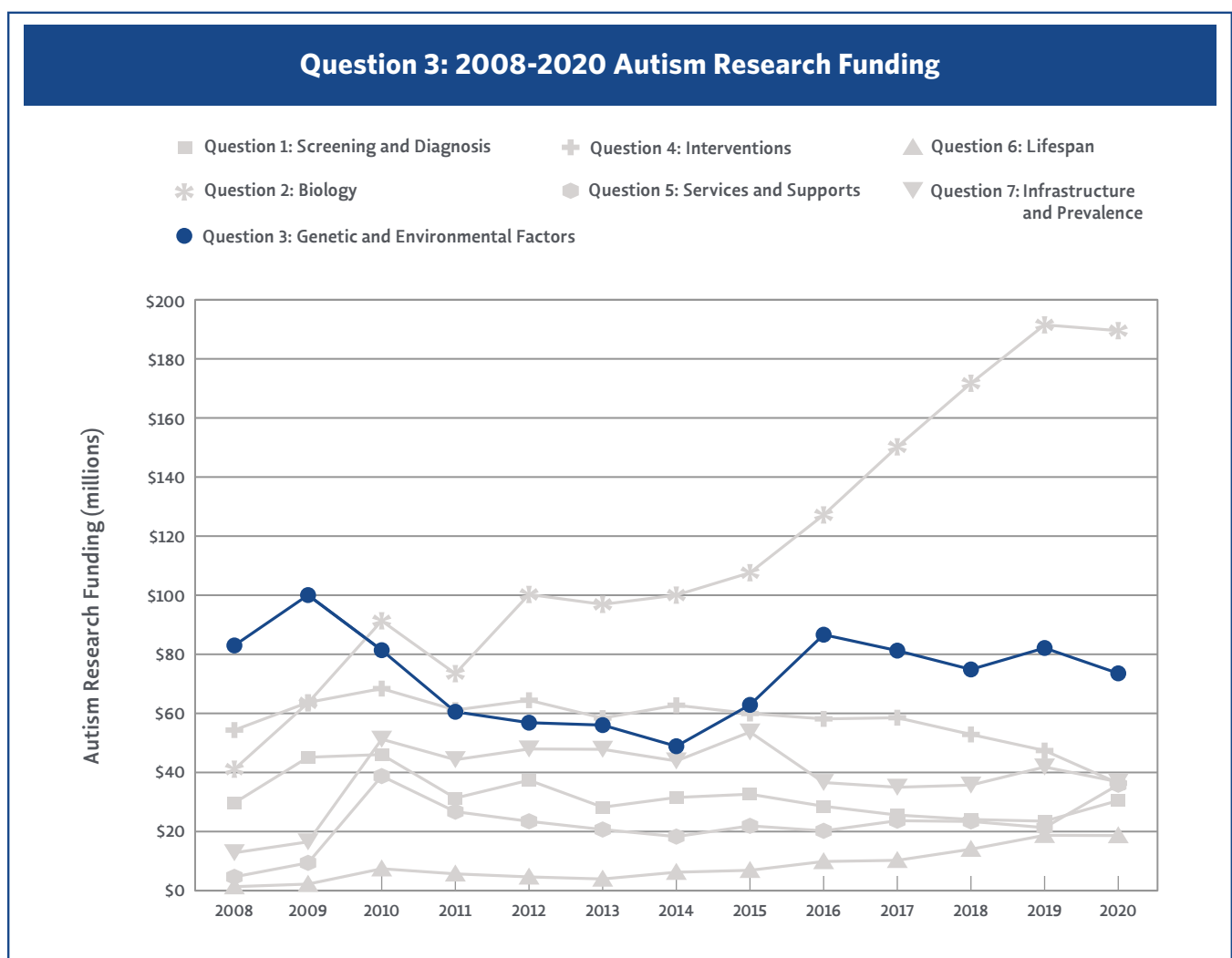

Figure 39. Question 3 autism research funding from 2008-2020. Over the 13-year span, funding for Question 3 initially showed an increase followed by a decrease from 2009 to 2014, a 78.6% increase between 2014 and 2016, and an overall decrease from 2016 to 2020.

Question 4:
INTERVENTIONS

ASPIRATIONAL GOAL: Develop a range of targeted treatments and interventions that optimize function and abilities across the lifespan to achieve meaningful outcomes and maximize quality of life for people on the autism spectrum.

RESEARCH FOCUS OF QUESTION 4

Question 4 asks "Which treatments and interventions will help?" and covers a range of interventions, including pharmacological, behavioral, educational, occupational, and technology-based approaches to address aspects of autism and its co-occurring conditions. Research in this field encompasses the development of new interventions using genetically targeted pharmacology and combination therapies as well as behavioral, occupational, and technology-based interventions that can be delivered in educational and other home- and community-based settings. Question 4 also encompasses research to ensure interventions include the whole autism spectrum and diverse populations.

ANALYSIS OF 2019-2020 QUESTION 4 PORTFOLIO

Research focused on interventions received $47.0 million (11.1%) of total autism funding in 2019. The number of projects assigned to Question 4 totaled 275 projects, which was 17.1% of all projects included in the portfolio. In 2020, funding towards Question 4 accounted for 8.6% of the portfolio ($35.8 million) and 15.1% of total projects (237 projects). Many agencies and organizations invest in interventions research; however, the funders with the largest contributions during this period were the National Institutes of Health, the Simons Foundation, the Health Resources and Services Administration, and the National Science Foundation. Question 4 has three Objectives. **Figures 40** and **41** provide a detailed overview of each Objective's funding and the number of projects assigned to each Objective in 2019 and 2020.

Every Objective in Question 4 was in progress and had funding for both years of the portfolio analysis. **Objective 4.1** includes research on pharmacological and medical interventions and accounted for 44.8% and 45.0% of Question 4 funding in 2019 and 2020, respectively. Objective 4.1 had 86 projects ($21.1

million) in 2019 and 77 projects ($16.1 million) in 2020. **Objective 4.2**, focused on the development of psychosocial and naturalistic interventions, was the second largest Objective in 2019 and 2020. In 2019, Objective 4.2 accounted for 35.4% of Question 4 funding ($16.6 million, 135 projects), while this Objective accounted for 34.4% of Question 4 funding in 2020 ($12.3 million, 112 projects). **Objective 4.3**, with the goal to optimize development of technology-based interventions, received the lowest levels of funding each year. Objective 4.3 received $8.7 million (18.5%) and had 51 projects in 2019 and $6.8 million (19.0%) and 45 projects in 2020. The rest of Question 4 funding went to projects categorized as Core/Other, which accounted for 1.2% of Question 4 funding ($579,894, 3 projects) in 2019 and 1.6% of Question 4 funding ($575,346, 3 projects) in 2020. Projects assigned to Core/Other included resiliency programs for siblings of individuals on the autism spectrum, interventions to improve tolerance of dental exams, and the development of animal models to test pharmacological interventions for autism.
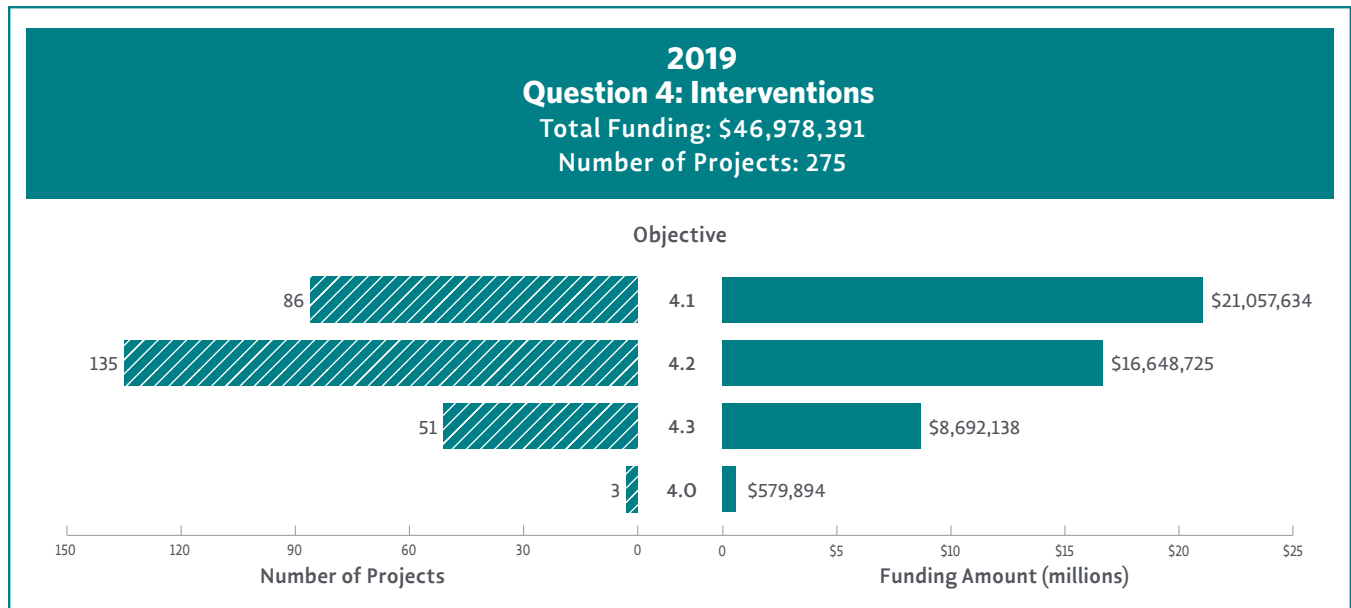
2019
Question 4: Interventions
Total Funding: $46,978,391
Number of Projects: 275

Objective

Number of Projects	Objective	Funding Amount (millions)
86	4.1	$21,057,634
135	4.2	$16,648,725
51	4.3	$8,692,138
3	4.0	$579,894

Figure 40. 2019 funding and number of projects for Question 4 Objectives. 4.1: Develop and improve pharmacological and medical interventions to address both core symptoms and co-occurring conditions in autism; 4.2: Create and improve psychosocial, developmental, and naturalistic interventions for core symptoms and co-occurring conditions in autism; 4.3: Maximize the potential for technologies and development of technology-based interventions to improve the lives of people on the autism spectrum; 4.O: Projects that do not align with Question 4 Objectives or support "core" activities in the autism research field "Core/Other."
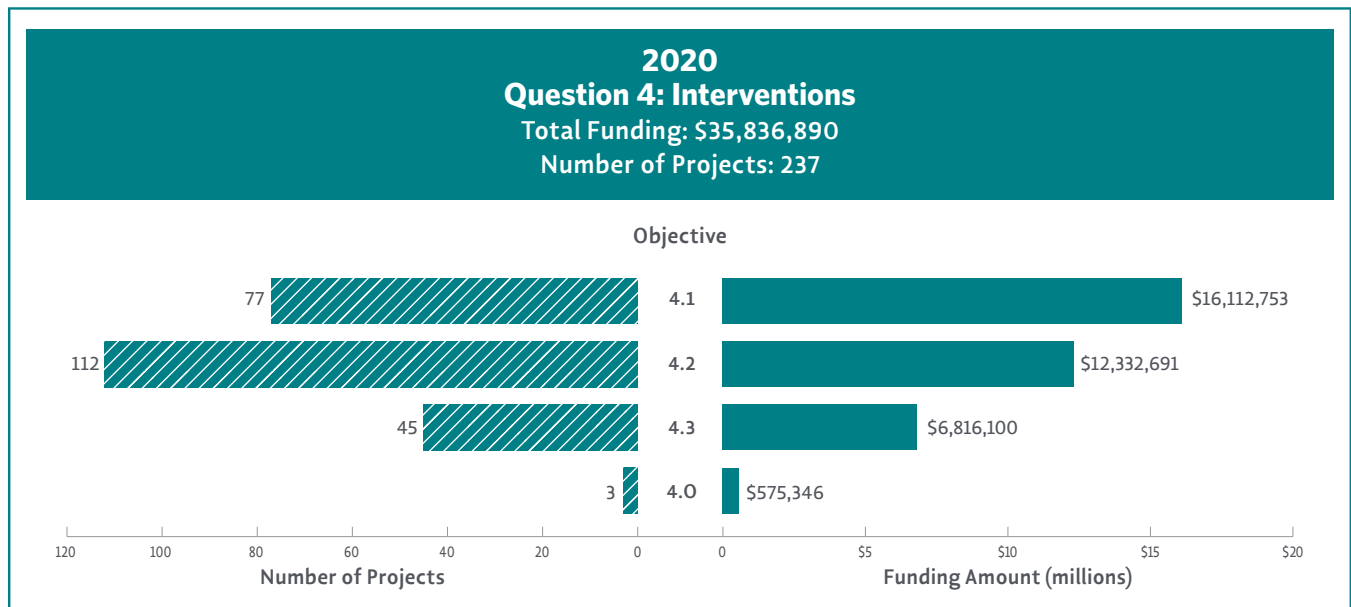

2020
Question 4: Interventions
Total Funding: $35,836,890
Number of Projects: 237

Objective

Number of Projects	Objective	Funding Amount (millions)
77	4.1	$16,112,753
112	4.2	$12,332,691
45	4.3	$6,816,100
3	4.0	$575,346

Figure 41. 2020 funding and number of projects for Question 4 Objectives. See Figure 40 caption for descriptions of each Objective.

QUESTION 4 SUBCATEGORY ANALYSIS

Question 4 represents research on a wide array of interventions for autism, ranging from medications to alleviate core and co-occurring symptoms, to behavioral therapies and technologies to improve communication, social skills, life skills, and learning. Projects under Question 4 were broken down into seven Subcategories: Behavioral; Complementary, Dietary, and Alternative; Educational; Medical/Pharmacologic; Model Systems/Therapeutic Targets; Occupational, Physical, and Sensory-Based; and Technology-Based interventions and supports (**Figures 42** and **43**).

The Subcategories for Question 4 illustrate the many approaches to interventions supported by autism research funders. **Medical/Pharmacologic** intervention research received the largest proportion of Question 4 funding in both 2019 and 2020, accounting for 28.8% of Question 4 funding (44 projects) in 2019 and 26.4% of Question 4 funding (35 projects) in 2020. The next largest amount of funding for 2019 and 2020 supported projects to develop **Behavioral** interventions (2019: 25.1%, 95 projects; 2020: 23.1%, 81 projects), including applied behavior analysis (ABA), cognitive therapy, and social skills training. **Technology-Based** interventions and supports received 21.4% of funding
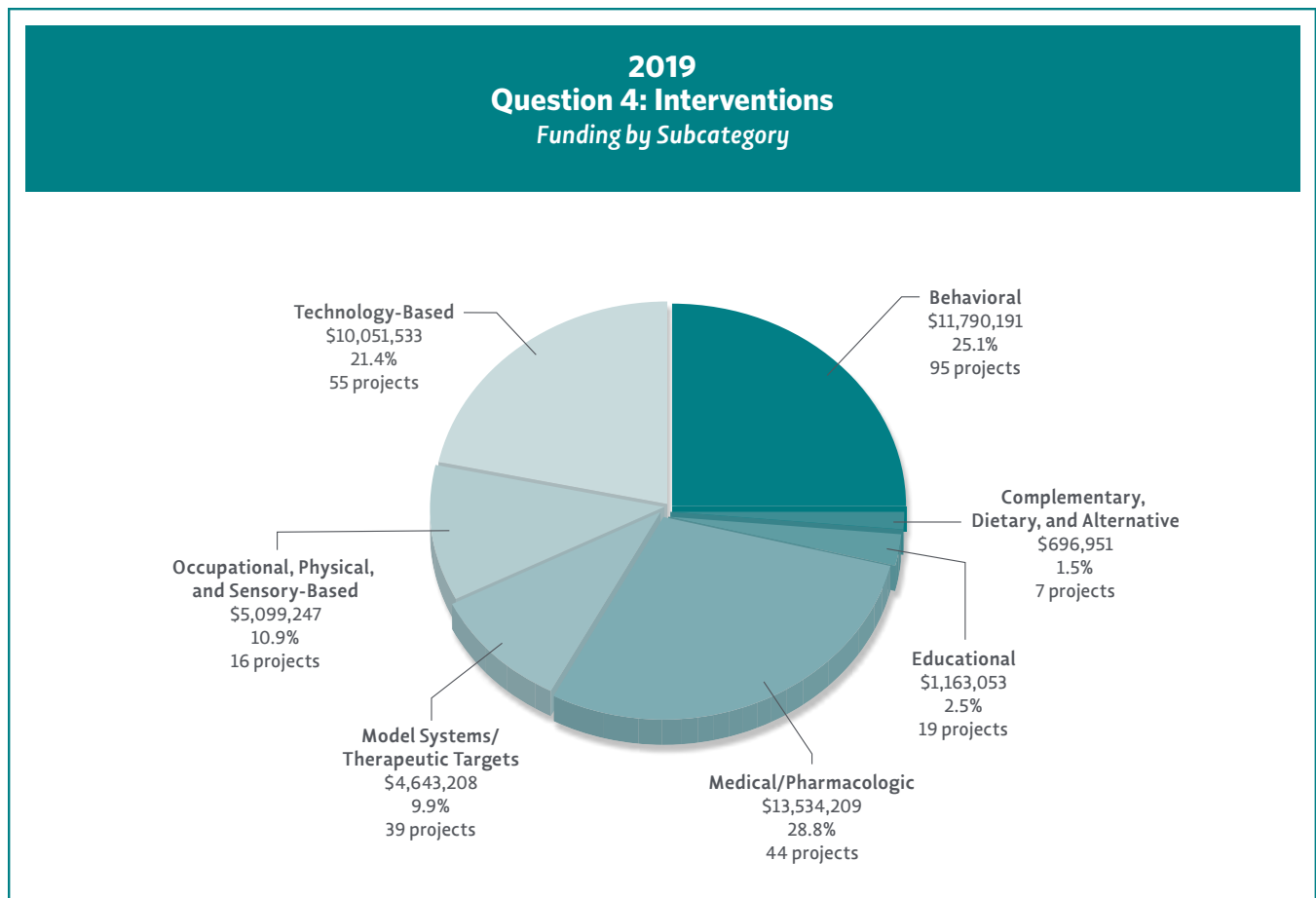

2019
Question 4: Interventions
Funding by Subcategory

Technology-Based
$10,051,533
21.4%
55 projects

Behavioral
$11,790,191
25.1%
95 projects

Complementary,
Dietary, and Alternative
$696,951
1.5%
7 projects

Occupational, Physical,
and Sensory-Based
$5,099,247
10.9%
16 projects

Educational
$1,163,053
2.5%
19 projects

Model Systems/
Therapeutic Targets
$4,643,208
9.9%
39 projects

Medical/Pharmacologic
$13,534,209
28.8%
44 projects

Figure 42. 2019 Question 4 funding by Subcategory.

(55 projects) in 2019 and 19.9% of funding in 2020 (49 projects). In 2019, research on **Occupational, Physical, and Sensory-Based** interventions received the next largest amount, accounting for 10.9% of Question 4 funding (16 projects). **Model Systems/Therapeutic Targets**, focusing on early development of animal and cellular models that mimic characteristics of autism to test experimental therapies, followed with 9.9% of Question 4 funding in 2019 (39 projects). This Subcategory was the fourth highest funded area in 2020 (18.7%, 37 projects). As described in the *2016 IACC Portfolio Analysis Report*, Objectives experienced a shift in the categorization of some projects using autism model systems due to the new

Objectives introduced in the *2016-2017 Strategic Plan*. Model systems projects were formerly all assigned to Question 4; however, under the *2016-2017 Strategic Plan*, some of these projects are now better aligned with Question 2, while those specifically focused on testing new drugs and interventions remained in Question 4. Projects on Occupational, Physical, and Sensory-Based interventions received 5.3% of funding in 2020 with 13 projects. The Subcategories with the smallest amounts of funding for both 2019 and 2020 included classroom-based **Educational** (2019: 2.5%, 19 projects; 2020: 4.0%, 14 projects) and **Complementary, Dietary, and Alternative** interventions (2019: 1.5%, 7 projects; 2020: 2.6%, 8 projects).
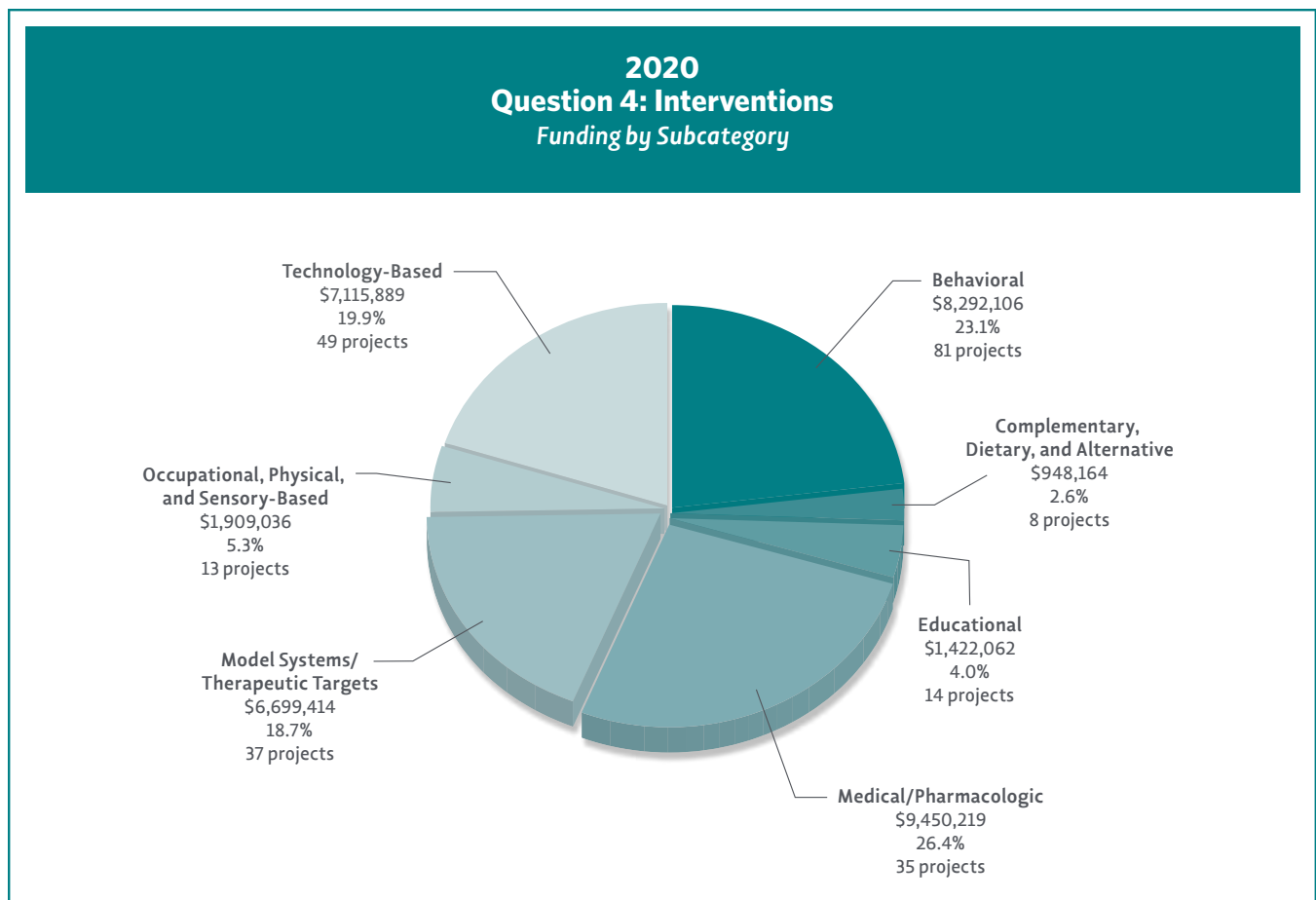

2020
Question 4: Interventions
Funding by Subcategory

Technology-Based
$7,115,889
19.9%
49 projects

Behavioral
$8,292,106
23.1%
81 projects

Complementary, Dietary, and Alternative
$948,164
2.6%
8 projects

Occupational, Physical, and Sensory-Based
$1,909,036
5.3%
13 projects

Educational
$1,422,062
4.0%
14 projects

Model Systems/ Therapeutic Targets
$6,699,414
18.7%
37 projects

Medical/Pharmacologic
$9,450,219
26.4%
35 projects

Figure 43. 2020 Question 4 funding by Subcategory.

QUESTION 4 FUNDING OVER TIME: 2008-2020

The trend in annual Question 4 funding over time is shown in **Figure 44**. Overall, research funding focused on interventions maintained a steadily moderate level from 2008 to 2017, even with the 2016 reassignment of some projects from Question 4 to Question 2 based on the newly formulated Objectives of *2016-2017 Strategic Plan*. There was a 19.3% decrease in funding between 2017 and 2019, and an additional 23.7% decrease from 2019 to 2020. It is notable that the number of projects (as opposed to funding amount) did not decrease from

2017 (273 projects) to 2019 (275 projects), indicating that research activity continued at similar rates, but the costs of some projects were lower than in the past. The decrease in funding observed in 2020 may in part reflect the impact of the pandemic in this particular area, as in-person research on interventions was difficult to conduct during this time. Future reports will continue to monitor whether this continues into 2021 and 2022.
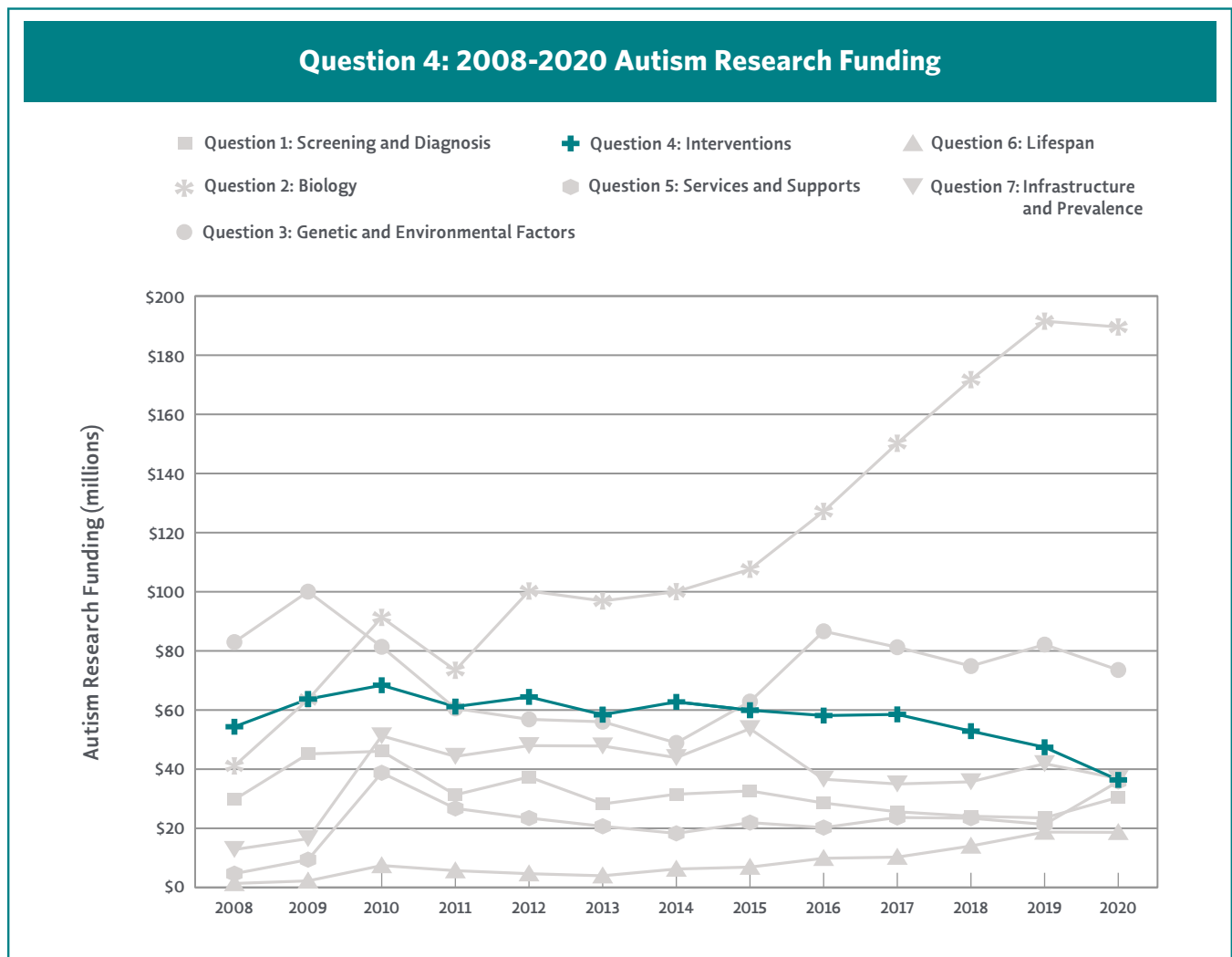
Figure 44. Question 4 autism research funding from 2008-2020. Funding for Question 4 remained primarily flat between 2008 and 2017, with a 19.3% decrease from 2017 to 2019 and a 23.7% decrease from 2019 to 2020.

Question 5:
SERVICES AND SUPPORTS

ASPIRATIONAL GOAL: Communities will develop, access, and implement high-quality, evidence-based services and supports that maximize quality of life and health across the lifespan for all people on the autism spectrum and their families.

RESEARCH FOCUS OF QUESTION 5

Question 5 ("What kinds of services and supports are needed to maximize quality of life for people on the autism spectrum?") focuses on funding research to develop and improve services and supports for people with autism and their families. Objectives address issues to improve the efficacy, cost-effectiveness, and dissemination of evidence-based practices in community settings; to support research to understand and develop strategies to address health disparities; and to develop better tools to measure autism services models at the federal, state, and local levels. Question 5 also includes support for research to develop and evaluate the training of service providers who work with individuals on the autism spectrum, particularly identifying culturally appropriate best practices.

ANALYSIS OF 2019-2020 QUESTION 5 PORTFOLIO

Projects assigned to Question 5 comprised 4.9% of total autism research in 2019 ($20.7 million) and consisted of 142 projects, which was 8.9% of all autism projects. In 2020, new investments made in this Question area by several funders (described in more detail on **page 68**) increased funding for Question 5 to 8.4% of the research portfolio ($35.3 million) and included 179 projects (11.4%). The largest funders of Question 5 were the National Institutes of Health, the Department of Education, and the Department of Defense – Army. Question 5 consists of three Objectives. **Figures 45** and **46** provide a detailed overview of each Objective's funding in 2019 and 2020 as well as the number of projects assigned to each Objective.

All three Objectives in Question 5 were in progress and received funding in 2019 and 2020. The majority of funding for this Question in 2019 went towards **Objective 5.3**, which supports developing and improving service models to enhance the quality of care that individuals receive from autism services. Objective 5.3 was 53.8% of the 2019 Question 5 portfolio, receiving $11.1 million in funding and included 104 projects. The next largest portion of 2019 funding

went to **Objective 5.1**, which addresses the gaps between research and practice when implementing evidence-based practices within the community. This Objective received $7.8 million (37.9%) in 2019 and had 20 projects. In 2020, Objective 5.1 received the largest portion of Question 5 funding at $18.6 million (52.7%) and 38 projects, followed by Objective 5.3, which received $14.9 million (42.2%) and 116 projects. **Objective 5.2**, research focused on reducing disparities in access to services for underserved populations, received $842,317 (4.1%) of funding in 2019, accounting for 16 projects, and $780,821 (2.2%) of funding in 2020, accounting for 22 projects. In 2019, Question 5 Core/Other received 4.2% of Question 5 funding, with $875,000 and two projects. In 2020, Question 5 Core/Other included 2.9% of total Question 5 funding ($1.0 million) and three projects. Projects assigned to Core/Other include those developing and testing measures to assess peer relationships and family involvement, improving community living and participation, and determining the impact of the COVID-19 pandemic on young children with autism and their families.
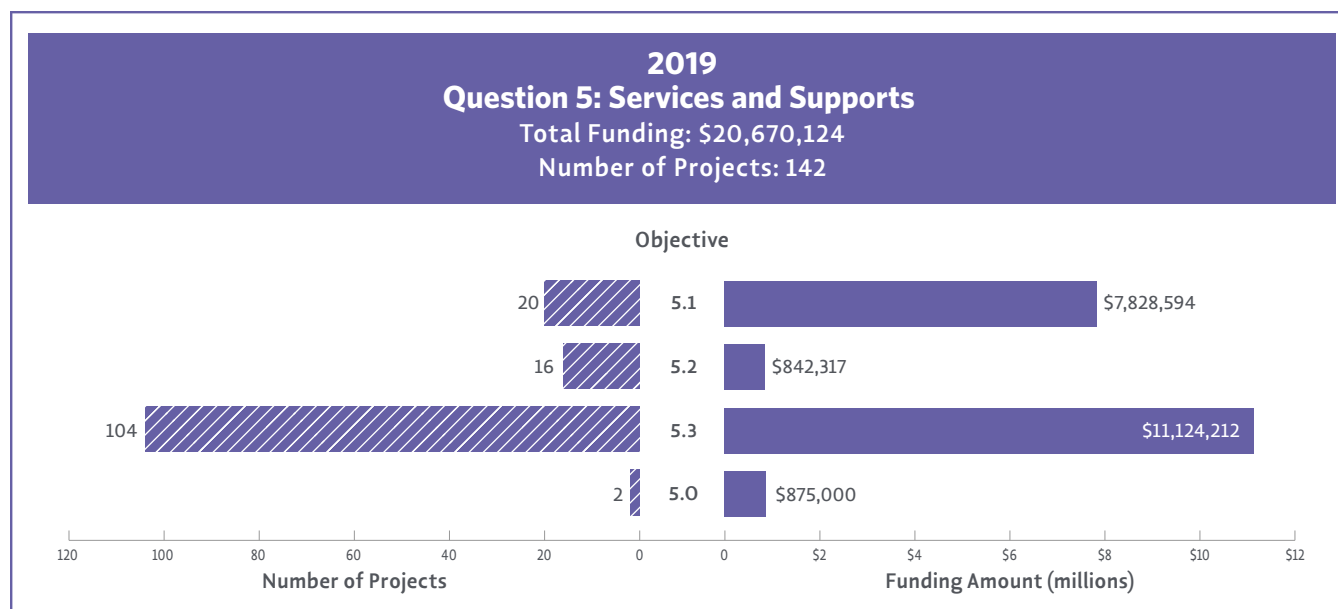
Figure 45. 2019 funding and number of projects for Question 5 Objectives. 5.1: Scale up and implement evidence-based interventions in community settings; 5.2: Reduce disparities in access and in outcomes for underserved populations; 5.3: Improve service models to ensure consistency of care across many domains with the goal of maximizing outcomes and improving the value that individuals get from services; 5.O: Projects that do not align with Question 5 Objectives or support "core" activities in the autism research field were labeled "Core/Other."
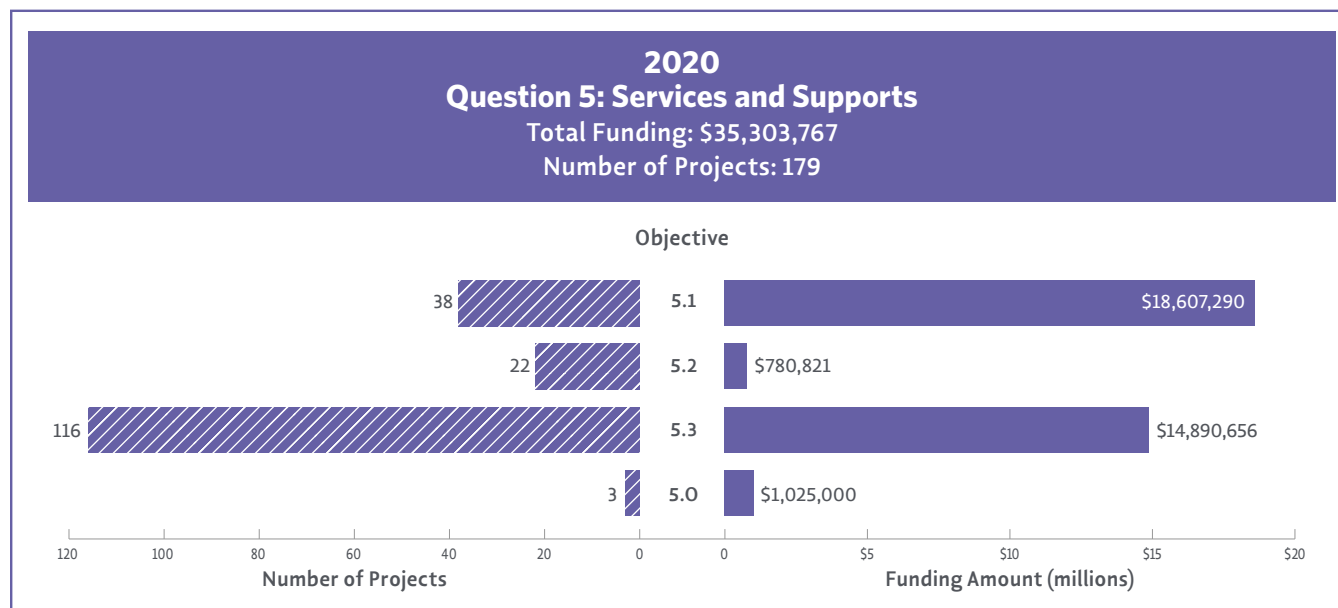
Figure 46. 2020 funding and number of projects for Question 5 Objectives. See Figure 45 caption for descriptions of each Objective.

QUESTION 5 SUBCATEGORY ANALYSIS

Projects within Question 5 are divided into five Subcategories that reflect the general scope of research on services and supports: Community Inclusion Programs; Efficacious and Cost-Effective Service Delivery; Family Well-Being and Safety; development and evaluation of Practitioner Training; and Services Utilization and Access (**Figures 47** and **48**).

Research assigned to the Subcategory **Services Utilization and Access** received the largest proportion of 2019 Question 5 funding at 35.4% and 31 projects. This Subcategory includes research focused on addressing disparities and potential barriers to access. This was followed by funding for research concerning the development and evaluation of **Practitioner**

Training, which accounted for 34.6% of 2019 Question 5 funding and 81 projects. Projects related to research on **Efficacious and Cost-Effective Service Delivery**, which covers research projects that assess current service delivery models as well as developing new and efficient ways of providing services, aligned with 26.8% of Question 5 funding (26 projects) in 2019, and **Family Well-Being and Safety** research projects followed with 3.1% of 2019 funding (2 projects). Projects categorized as **Community Inclusion Programs**, which focuses on programs to provide instructions in social, communication, and leisure skills to support the participation of autistic children in fully integrated settings, received less than 1% of 2019 Question 5 funding (2 projects). In 2020, funding for Practitioner
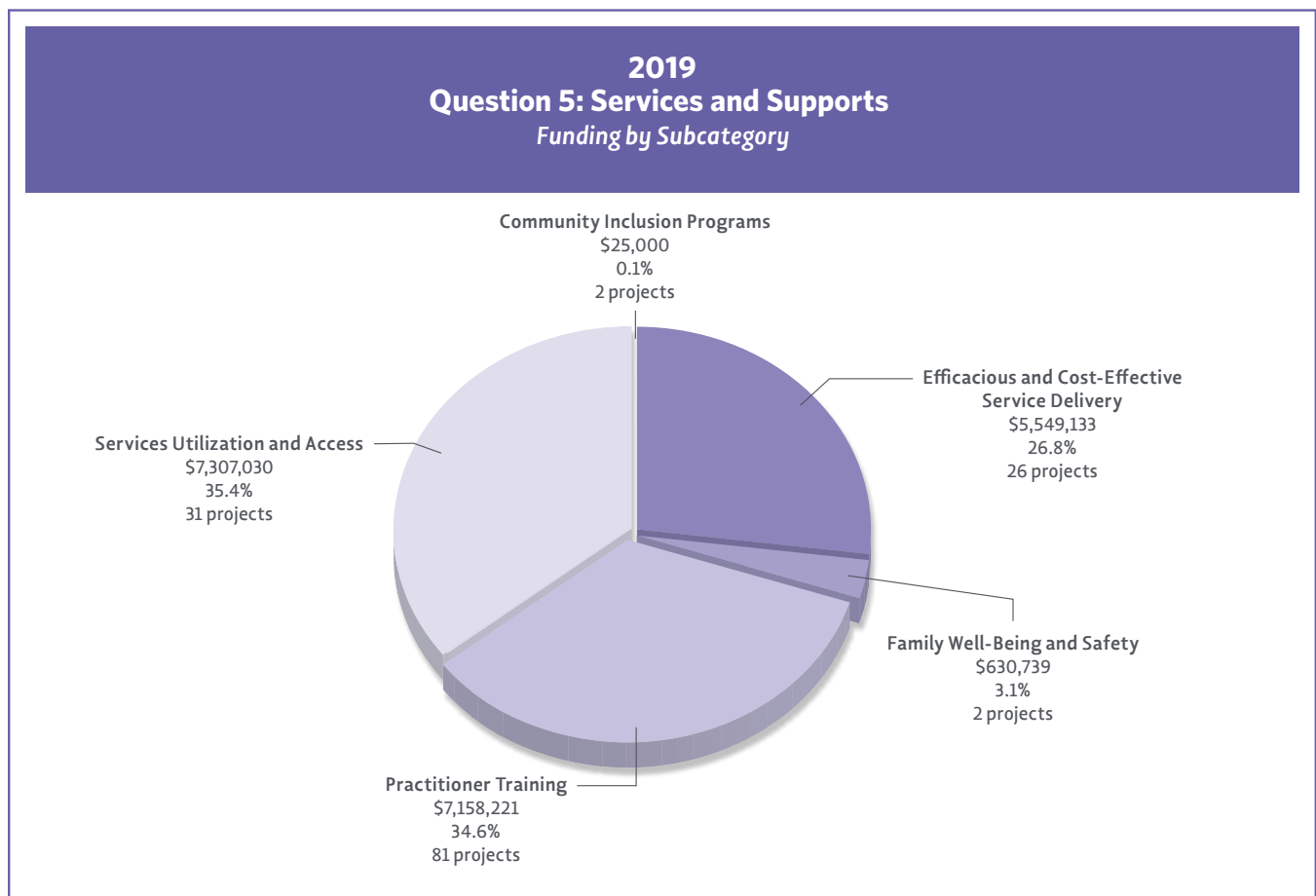

2019
Question 5: Services and Supports
Funding by Subcategory

Community Inclusion Programs
$25,000
0.1%
2 projects

Efficacious and Cost-Effective
Service Delivery
$5,549,133
26.8%
26 projects

Services Utilization and Access
$7,307,030
35.4%
31 projects

Family Well-Being and Safety
$630,739
3.1%
2 projects

Practitioner Training
$7,158,221
34.6%
81 projects

Figure 47. 2019 Question 5 funding by Subcategory.

Training made up the majority of Question 5 funding at 51.7% and 81 projects. This was followed by funding for research on Efficacious and Cost-Effective Service Delivery (30.0%, 55 projects). Service Utilization and Access made up 14.4% of 2020 Question 5 funding with 36 projects, and research on Family Well-Being and Safety accounted for 2.5% (4 projects) of Question 5 funding in 2020. Community Inclusion Programs received 1.3% of funding in 2020 with three projects.
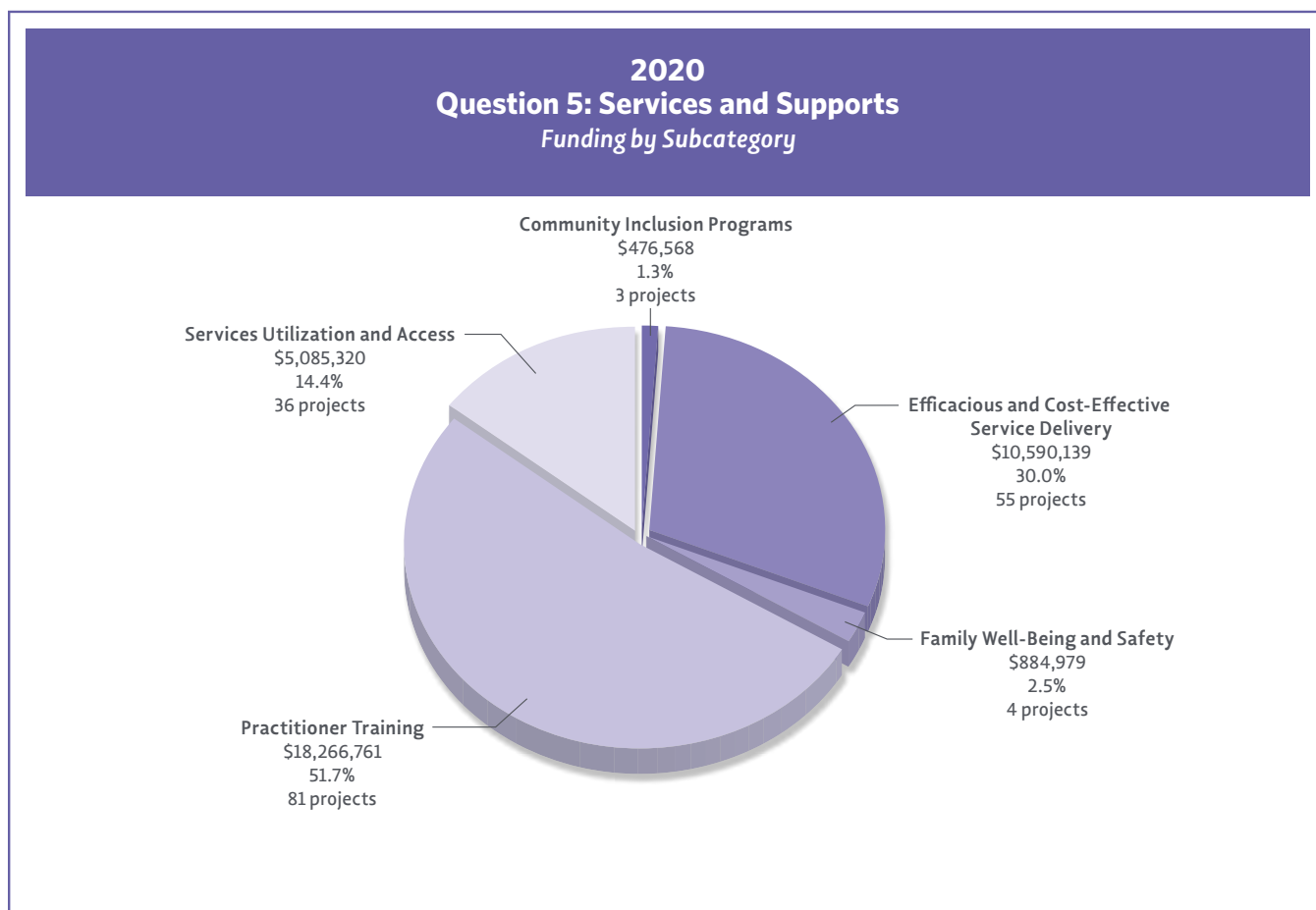
2020
Question 5: Services and Supports
Funding by Subcategory

Community Inclusion Programs
$476,568
1.3%
3 projects

Services Utilization and Access
$5,085,320
14.4%
36 projects

Efficacious and Cost-Effective
Service Delivery
$10,590,139
30.0%
55 projects

Family Well-Being and Safety
$884,979
2.5%
4 projects

Practitioner Training
$18,266,761
51.7%
81 projects

Figure 48. 2020 Question 5 funding by Subcategory.

QUESTION 5 FUNDING OVER TIME: 2008-2020

Figure 49 illustrates Question 5 funding over time. Research related to Question 5 has been funded at relatively low levels when compared to other Question areas. After 2010,[4] funding for projects within Question 5 decreased and then remained relatively stable between 2014 to 2019. In 2020, Question 5 experienced a 70.8% increase in funding compared to 2019, with large increases in investment from the

---

4   As explained in prior Portfolio Analysis Reports, adjustments in reporting were made to the 2010 portfolio to only report autism-specific and research-related portions of large, broad disability projects that are included in Question 5. **Figure 49** displays Question 5 funding in 2010 using this criteria to enable a more accurate comparison among all the years of analysis. The projects that included practitioner training were prorated starting in 2011 to include only the portion of funding pertaining to development and evaluation of training and not portions related to delivery of training.

Department of Defense – Army ($5.1 million increase), National Institutes of Health ($3.7 million increase), Department of Education ($3.0 million increase), and the Patient-Centered Outcomes Research Institute ($2.4 million increase). Coupled with the large proportion of new projects for Question 5 in 2019 and 2020, this increase in funding may reflect funders' growing recognition of the importance of research in this area and responsiveness to the recommendations of the IACC that call for increased investments for research on evidence-based services.

Question 5: 2008-2020 Autism Research Funding

Legend:
- ■ Question 1: Screening and Diagnosis
- ✳ Question 2: Biology
- ● Question 3: Genetic and Environmental Factors
- ✚ Question 4: Interventions
- ⬣ Question 5: Services and Supports
- ▲ Question 6: Lifespan
- ▼ Question 7: Infrastructure and Prevalence
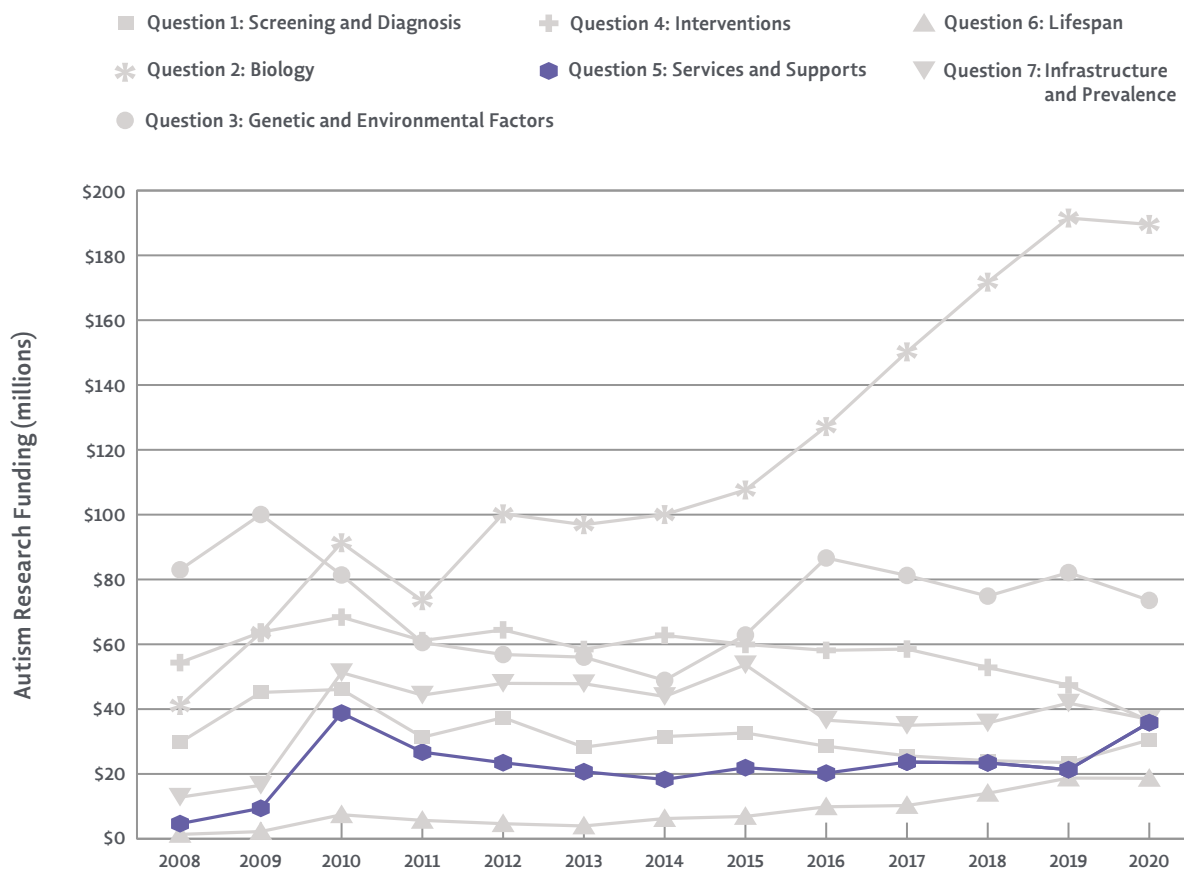
Figure 49. Question 5 autism research funding from 2008-2020. Compared to other Strategic Plan Questions, funding for Question 5 remained relatively low over the 13-year span. However, there was a 70.8% increase in funding for Question 5 from 2019 to 2020.

Question 6:
LIFESPAN

ASPIRATIONAL GOAL: All people with autism will have the opportunity to lead self-determined lives in the community of their choice, through school, work, community participation, satisfying relationships, and meaningful access to services and supports.

RESEARCH FOCUS OF QUESTION 6

With increasing societal awareness of the needs of people on the autism spectrum across the lifespan, Question 6 asks, "How can we meet the needs of people with autism as they progress into and through adulthood?" Question 6 encompasses research to identify and address issues related to the transition to adulthood such as housing and employment, improving the physical and mental health of adults, and incorporating acceptance and independence of people with autism in services and outreach efforts.

Some of the research in Question 6 represents projects that assess outcome measures such as well-being, health, independence, and employment for people on the autism spectrum, particularly with respect to the interventions and services they might have received. Many projects assigned to Question 6 focus on adolescents transitioning from the secondary education system to higher education and/or employment, as well as vocational/job skills and social skills training for both transition-age youth and adults.

ANALYSIS OF 2019-2020 QUESTION 6 PORTFOLIO

Research on Lifespan issues associated with autism (Question 6) accounted for 4.3% of total funding in both 2019 and 2020 ($18.1 million in 2019 and $18.0 million in 2020) and included 90 projects (5.6% of total projects) and 95 projects (6.0% of total projects), respectively. This Question area had the smallest portion of funding and number of projects for each year of the portfolio analysis. The agencies and organizations with the largest investments in this research in 2019 and 2020 were the National Institutes of Health, the National Science Foundation, the Administration for Community Living, and the Department of Defense – Army. As mentioned in an earlier section of this report, and similar to 2017 and 2018, Question 6 saw the largest proportion of funding for new projects in 2019 and 2020. This may indicate increasing interest among autism research funders in supporting projects in this area and responsiveness to the recommendation in the *2016-2017 IACC Strategic Plan* to prioritize funding for research on lifespan issues. Question 6 has three Objectives. **Figures 50** and **51** provide a detailed overview of each Objective's funding as well as the number of projects assigned to each Objective.

For both 2019 and 2020, all three Objectives assigned to Question 6 were in progress and received funding. In 2019, the largest portion of funding went to **Objective 6.1**, research supporting the transition to adulthood, accounting for 46.6% of Question 6 funding ($8.4 million, 48 projects). Objective 6.1 received the second largest proportion of funding for 2020, totaling $5.7 million (31.7%, 44 projects). Research focused on community integration, **Objective 6.3**, accounted for 42.2% of 2019 Question 6 funding with $7.6 million and 24 projects. In 2020, this Objective received the majority of Question 6 funding at 51.5% ($9.3 million) and included 33 projects. The goal of **Objective 6.2** is to conduct research to enhance health and well-being and reduce the disabling effects of co-occurring conditions. This Objective received $2.0 million (11.2%) in 2019 and included 16 projects. In 2020, Objective 6.2 received $3.0 million (16.8%) and contained 18 projects. Two projects in Question 6 were categorized as Core/Other in 2019, accounting for less than 1% of Question 6 funding ($100). These projects focused on studying the outcomes of behavioral interventions. No projects were categorized as Core/Other in 2020.
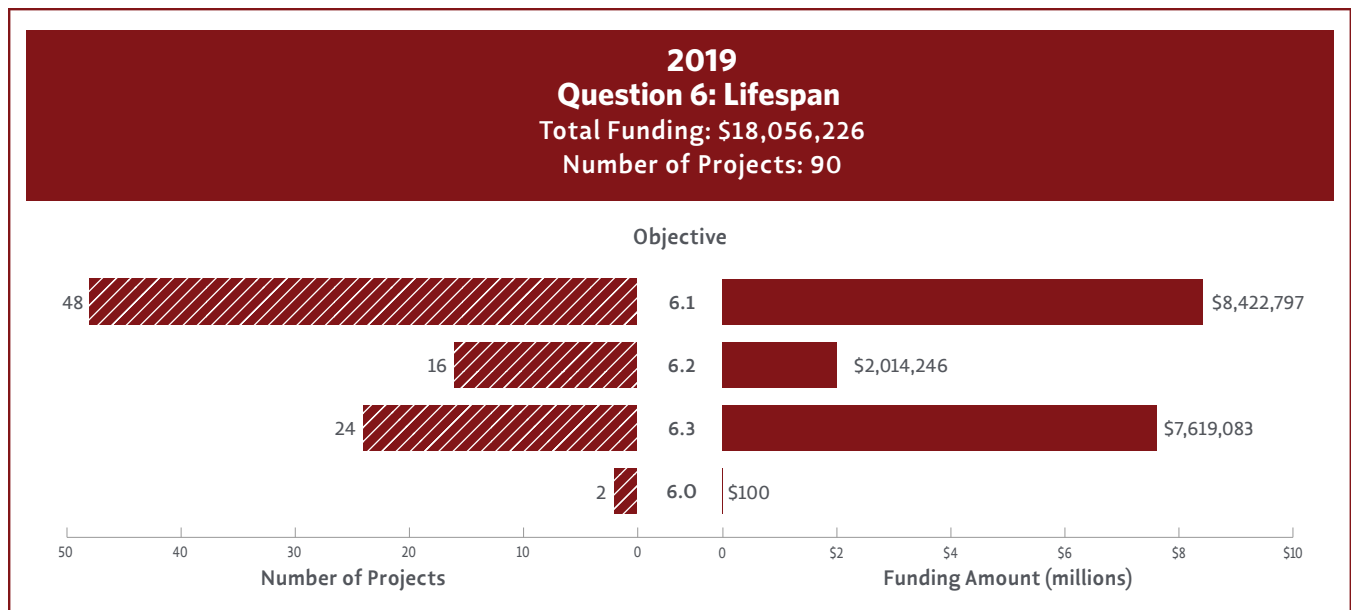
2019
Question 6: Lifespan
Total Funding: $18,056,226
Number of Projects: 90

Objective

Number of Projects	Objective	Funding Amount (millions)
48	6.1	$8,422,797
16	6.2	$2,014,246
24	6.3	$7,619,083
2	6.0	$100

Figure 50. 2019 funding and number of projects for Question 6 Objectives. 6.1: Support development and coordination of integrated services to help youth make a successful transition to adulthood and provide supports throughout the lifespan; 6.2: Support research and implement approaches to reduce disabling co-occurring physical and mental health conditions in adults with autism, with the goal of improving safety, reducing premature mortality, and enhancing quality of life; 6.3: Support research, services activities, and outreach efforts that facilitate and incorporate acceptance, accommodation, inclusion, independence, and integration of people on the autism spectrum into society; 6.O: Projects that do not align with Question 6 Objectives or support "core" activities in the autism research field were labeled "Core/Other."

2020
Question 6: Lifespan
Total Funding: $17,969,273
Number of Projects: 95

Objective

Number of Projects	Objective	Funding Amount (millions)
44	6.1	$5,693,631
18	6.2	$3,013,370
33	6.3	$9,262,273
0	6.0	$0
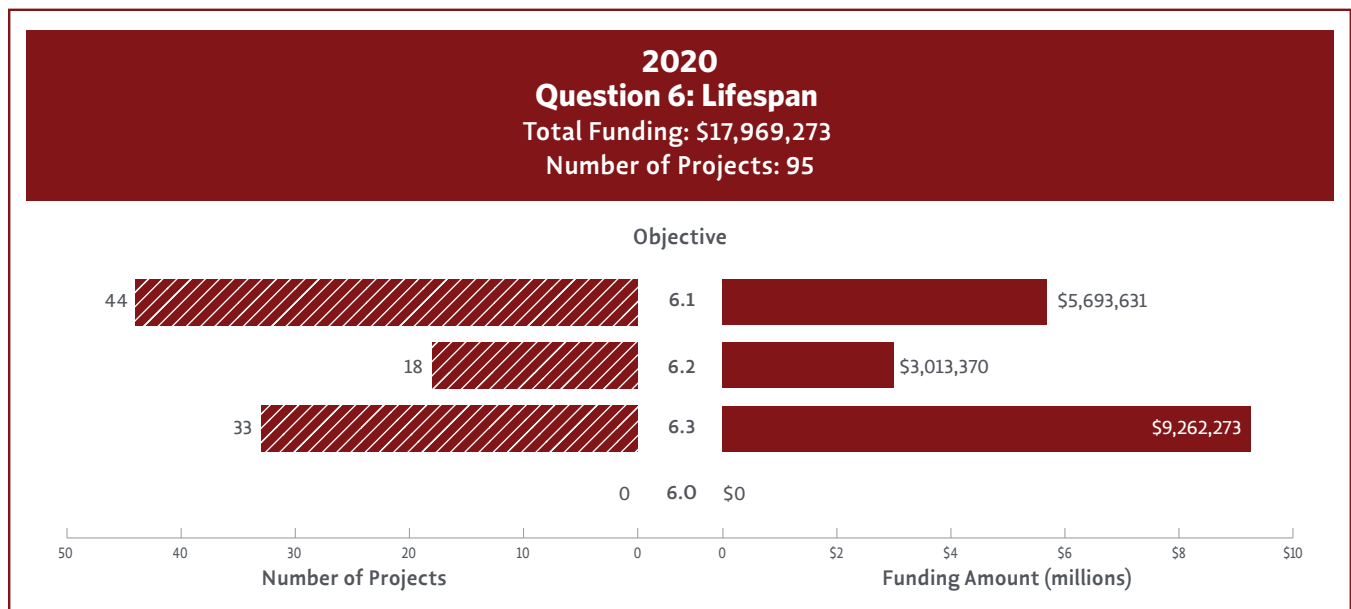
Figure 51. 2020 funding and number of projects for Question 6 Objectives. See Figure 50 caption for descriptions of each Objective.

QUESTION 6 SUBCATEGORY ANALYSIS

From 2010-2016, the number of projects aligned with Question 6 was relatively low, limiting the opportunity to create Subcategories within Question 6. However, there was a substantial increase in the number of projects aligned with Question 6 in 2017 and 2018, allowing projects for these years to be divided into Subcategories. Based on the projects in the portfolio, in addition to priority areas discussed at IACC meetings, Question 6 was divided into five Subcategories to track trends in subtopics of research on autism across the lifespan: Transition to Adulthood and Postsecondary Outcomes; Community Integration Supports and Services; Health and Behavioral Outcomes; Health Care Systems/Health Care Transitions; and Daily Life Skills (**Figures 52** and **53**).

In 2019 and 2020, the largest Subcategory was **Transition to Adulthood and Postsecondary Outcomes**, which focuses on improving services and interventions during this transition period as well as understanding life outcomes after high school, such as employment and college. In 2019, this Subcategory received 54.1% of Question 6 funding and included 36 projects. In 2020, this Subcategory received 51.6% of funding and totaled 41 projects. Projects developing **Community Integration Supports and Services** aim to increase inclusion of autistic adults in community settings while also developing interventions and supports that improve community involvement among youth and adults with autism. This Subcategory
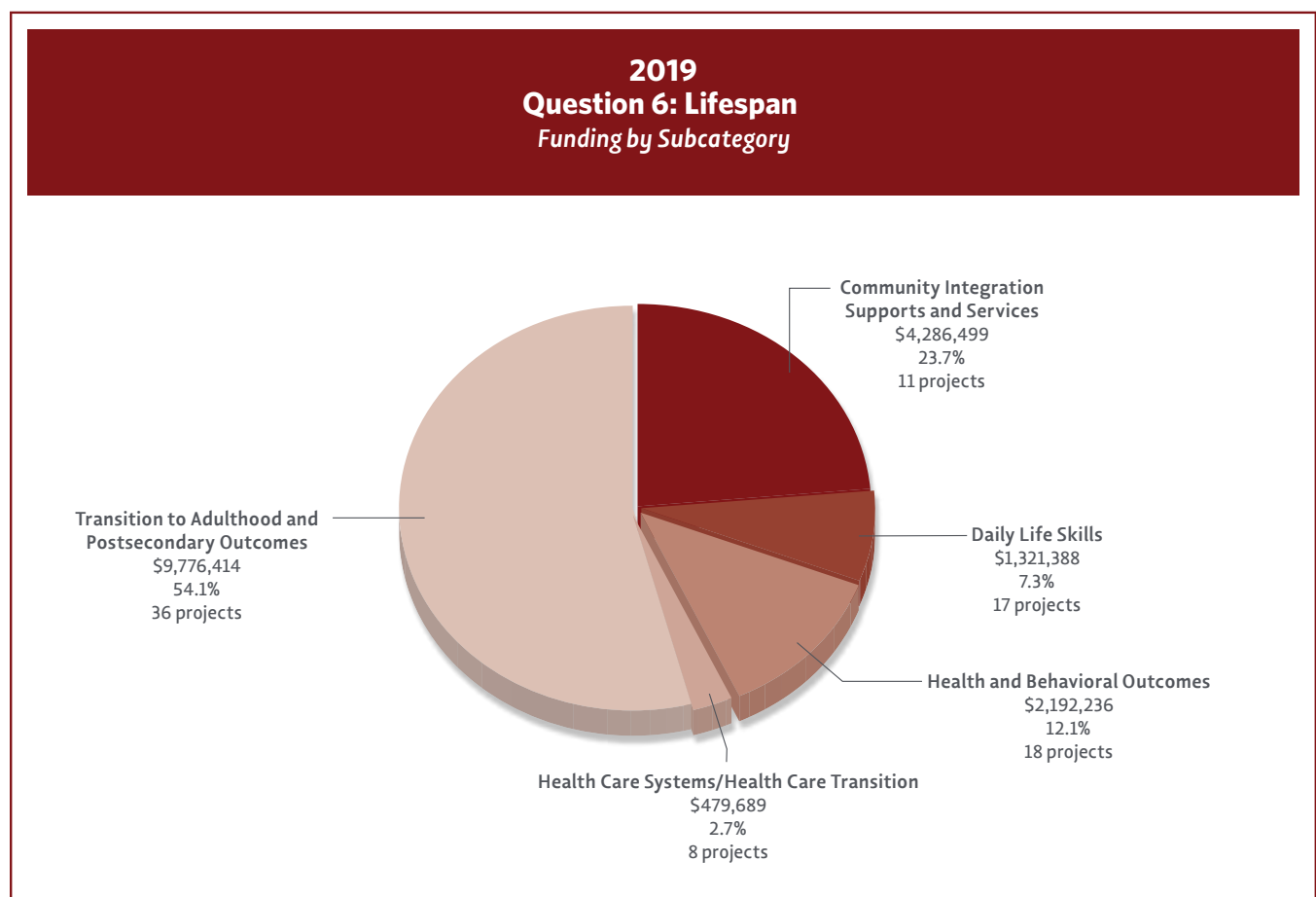

Figure 52. 2019 Question 6 funding by Subcategory.

received 23.7% of funding in 2019 (11 projects) and 21.9% of funding in 2020 (15 projects). **Health and Behavioral Outcomes** focuses on understanding health-related outcomes for youth and adults, including interventions for autism and co-occurring conditions; this Subcategory accounted for 12.1% of Question 6 funding in 2019 (18 projects) and 15.4% of funding in 2020 (19 projects). **Daily Life Skills** include projects that teach independent living skills, such as self-determination and goal setting, to youth and adults.

Daily Life Skills accounted for 7.3% (17 projects) and 6.6% (12 projects) of Question 6 funding in 2019 and 2020, respectively. **Health Care Systems/Health Care Transitions** includes projects focused on improving provider-patient experiences and the development of specific screening and diagnostic tools for autism in adults and co-occurring conditions related to autism. In 2019 and 2020, this Subcategory had eight projects active in each year, aligning with 2.7% and 4.4% of Question 6 funding, respectively.

2020
Question 6: Lifespan
Funding by Subcategory

Community Integration Supports and Services
$3,930,696
21.9%
15 projects

Daily Life Skills
$1,194,923
6.6%
12 projects

Health and Behavioral Outcomes
$2,770,461
15.4%
19 projects

Health Care Systems/Health Care Transition
$793,660
4.4%
8 projects

Transition to Adulthood and Postsecondary Outcomes
$9,279,534
51.6%
41 projects
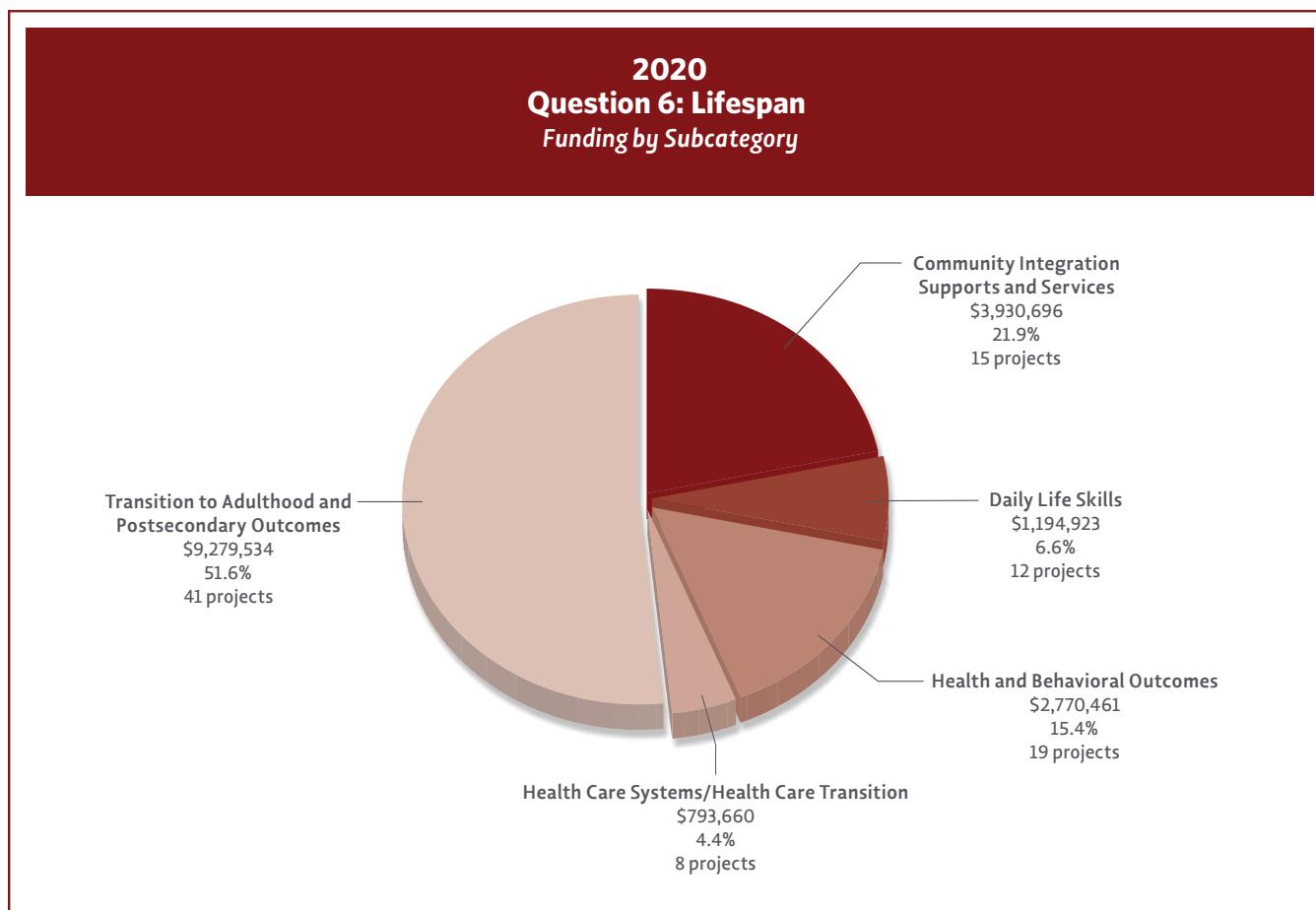
Figure 53. 2020 Question 6 funding by Subcategory.

QUESTION 6 FUNDING OVER TIME: 2008-2020

Research related to Question 6 has received the lowest level of annual funding for every year of the 13-year portfolio analysis period (**Figure 54**). Following a small increase from 2009 to 2010, Question 6 funding decreased between 2010 and 2013. Since 2013, funding for Question 6 has experienced relatively small but steady increases. Additionally, the number of projects assigned to this Question area has grown, from eight projects in 2008 to 95 projects in 2020, a more than 1,000% increase. In the *2016-2017 IACC Strategic Plan*,

the IACC recommended a doubling of autism research funding, including increased funding for research to understand and address the needs of transition-age youth, young adults, and older adults on the autism spectrum. The recent increases in funding amount and number of projects, especially for newly initiated projects in recent years, indicate that research in this Question area is growing as the autism community increases its focus on supporting research that covers the full lifespan.
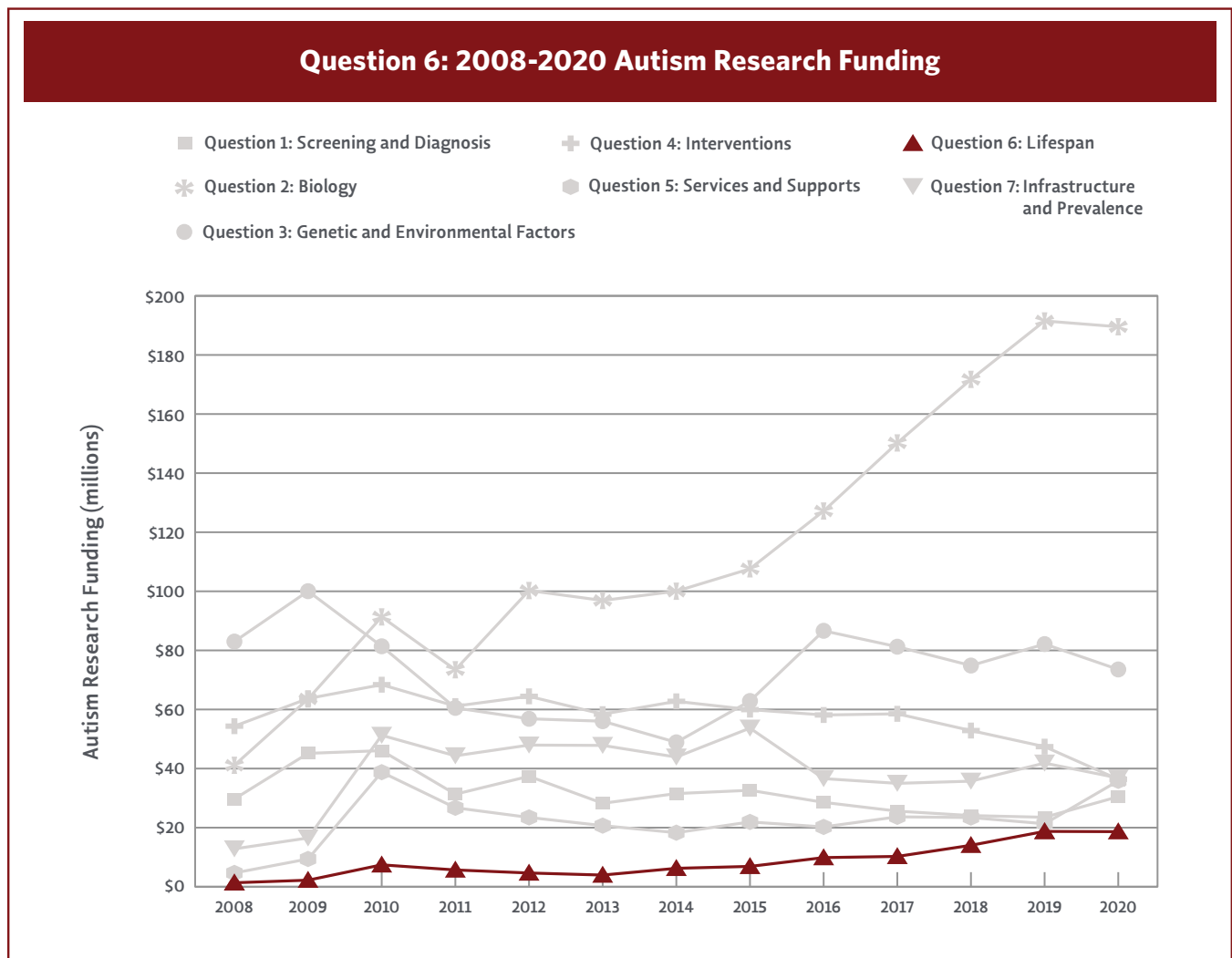
Figure 54. Question 6 autism research funding from 2008-2020. Funding for Question 6 remained low over the 13-year span but has been experiencing steady increases since 2013.

Question 7:
INFRASTRUCTURE AND PREVALENCE

ASPIRATIONAL GOAL: Develop, enhance, and support infrastructure and surveillance systems that advance the speed, efficacy, and dissemination of autism research and services.

RESEARCH FOCUS OF QUESTION 7

Question 7 ("How do we continue to build, expand, and enhance the infrastructure system to meet the needs of the autism community?") covers the topics of research infrastructure, biorepositories, data sharing, and studies of autism prevalence. There is also a focus on communication/dissemination of research findings and evidence-based practices, as well as developing the professional workforce that conducts autism research and provides services to individuals with autism and their families.

ANALYSIS OF 2019-2020 QUESTION 7 PORTFOLIO

Projects assigned to Question 7 comprised 9.8% ($41.4 million) of total autism research funding in 2019 and consisted of 154 projects, which was 9.6% of the total number of projects. In 2020, Question 7 accounted for 8.7% of total funding ($36.3 million) and 9.1% of total projects (143 projects). In 2019, the National Institutes of Health, the Simons Foundation, the National Science Foundation, and the Centers for Disease Control and Prevention were the largest funders of Question 7 research. In 2020, the top four funders for Question 7 research were the National Institutes of Health, the Simons Foundation, the Centers for Disease Control and Prevention, and Autism Speaks. Question 7 consists of four Objectives. **Figures 55** and **56** provide a detailed overview of each Objective's funding as well as the number of projects assigned to each Objective.

All four of Question 7's Objectives were in progress and received funding in 2019 and 2020. **Objective 7.3**, focused on enhancing the research workforce and developing interdisciplinary training, received the largest proportion of Question 7 funding in 2019 and 2020, accounting for 31.4% ($13.0 million) of Question 7 funding in 2019 with 62 projects and 25.8% ($9.4 million) of Question 7 funding in

2020 with 57 projects. The next largest portion of funding went towards **Objective 7.2**, which focuses on developing and enhancing data banks and data sharing. Objective 7.2 received $12.3 million (29.7%) in 2019 with 24 projects and $8.4 million (23.0%) in 2020 with 20 projects. **Objective 7.1**, which supports increasing biospecimen donations and encouraging integration of biorepository banks, followed with 13.5% ($5.6 million) of Question 7 funding in 2019 and had 19 projects; in 2020, this Objective accounted for 20.9% ($7.6 million) of Question 7 funding and 31 projects. **Objective 7.4** received $5.4 million (13.1%) of Question 7 funding in 2019 with 18 projects and $6.0 million (16.6%) of 2020 Question 7 funding with 11 projects; this Objective supports the expansion of systems to conduct epidemiological studies on autism prevalence. In 2019, there were 31 projects, accounting for $5.1 million (12.3%), that did not fit into a specific Question 7 Objective and were assigned to Core/Other. Comparably, there were 24 projects with $4.9 million (13.5%) in funding towards Core/Other in 2020. Projects assigned to Core/Other include data and administrative centers for large, multisite research projects.
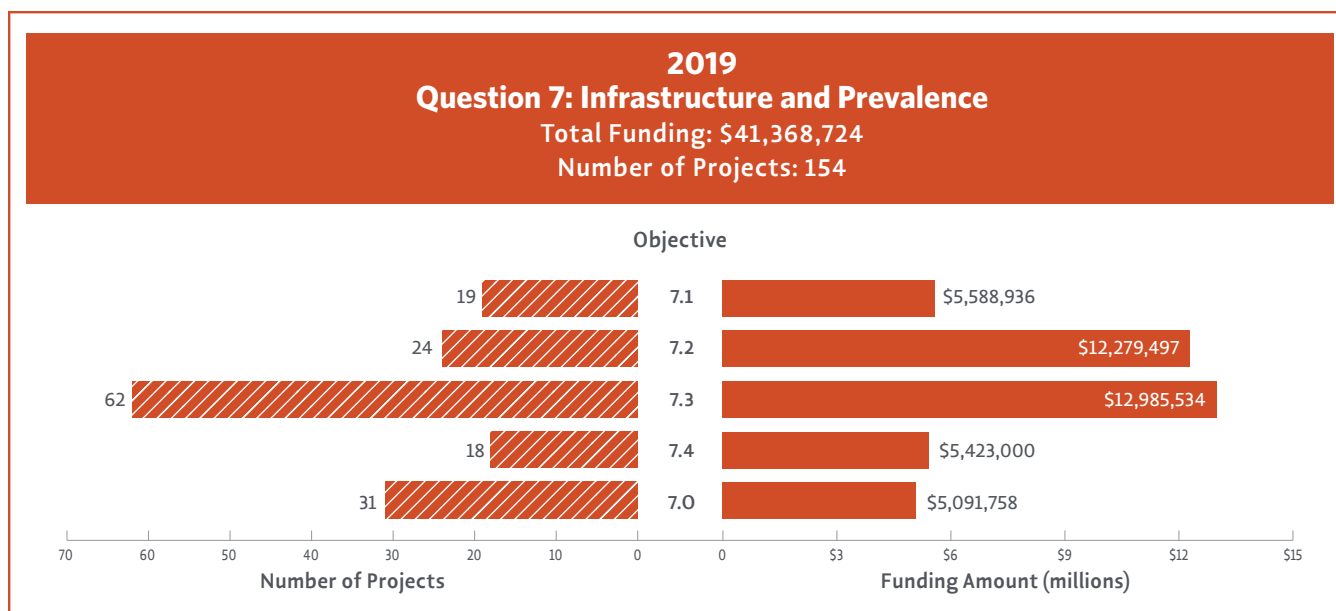
2019
Question 7: Infrastructure and Prevalence
Total Funding: $41,368,724
Number of Projects: 154

Objective

	Number of Projects		Funding Amount (millions)
7.1	19		$5,588,936
7.2	24		$12,279,497
7.3	62		$12,985,534
7.4	18		$5,423,000
7.O	31		$5,091,758

Figure 55. 2019 funding and number of projects for Question 7 Objectives. 7.1: Promote growth, integration, and coordination of biorepository infrastructure; 7.2: Develop, enhance, and link data repositories; 7.3: Expand and enhance the research and services workforce, and accelerate the pipeline from research to practice; 7.4: Strengthen autism surveillance systems to further understanding of the population of individuals with autism, while allowing comparisons and linkages across systems as much as possible; 7.O: Projects that do not align with Question 7 Objectives or support "core" activities in the autism research field were labeled "Core/Other."

2020
Question 7: Infrastructure and Prevalence
Total Funding: $36,293,536
Number of Projects: 143

Objective

	Number of Projects		Funding Amount (millions)
7.1	31		$7,597,792
7.2	20		$8,357,209
7.3	57		$9,381,827
7.4	11		$6,041,899
7.O	24		$4,914,810
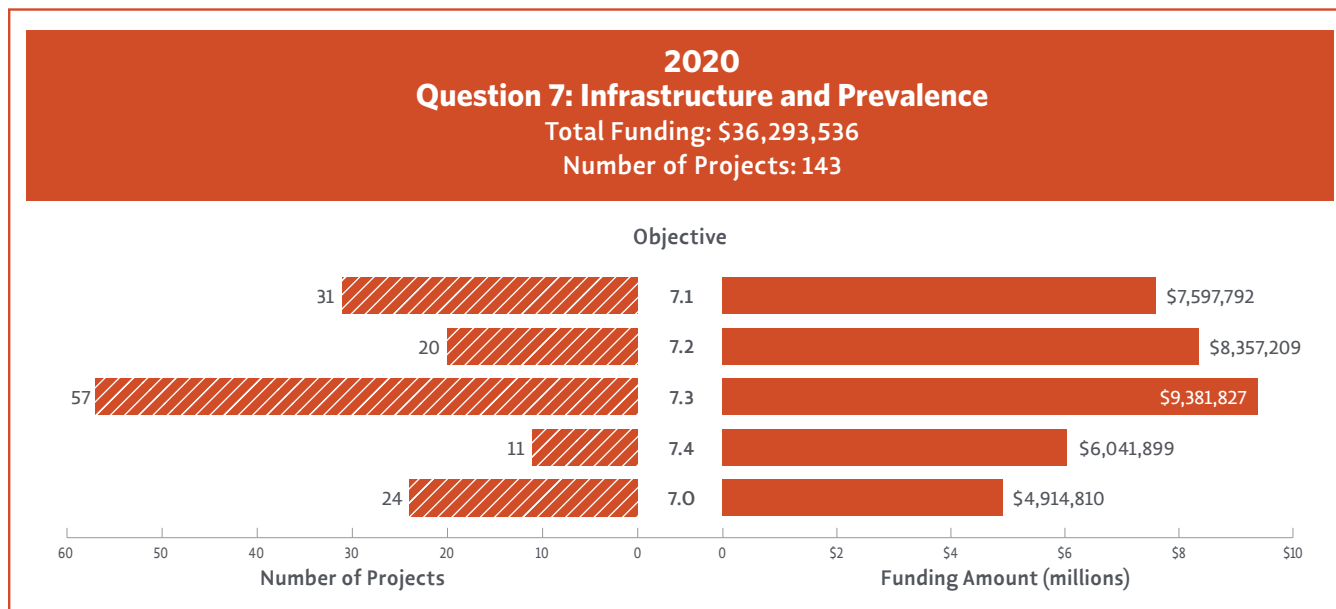
Figure 56. 2020 funding and number of projects for Question 7 Objectives. See Figure 55 caption for descriptions of each Objective.

QUESTION 7 SUBCATEGORY ANALYSIS

The six Subcategories in Question 7 reflect the broad array of autism research infrastructure needs that have been identified by the IACC: Biobanks; Data Tools; Prevalence Studies; Research Infrastructure; Research Recruitment and Clinical Care; and Research Workforce Development (**Figures 57** and **58**).

In Question 7, funding is distributed relatively evenly across the Subcategories, which encompass a diverse set of project types. In 2019 and 2020, **Data Tools** received the largest portion of funding (2019: 31.6%, 25 projects; 2020: 31.1%, 25 projects); this Subcategory includes projects such as the National Database for

Autism Research (NDAR; now the **National Institute of Mental Health Data Archive [NDA]**) and **MSSNG**, a collaboration between Autism Speaks and Google to create the world's largest genomic database on autism. **Research Workforce Development**, which supports conferences and training for autism researchers, received the next largest proportion of funding in 2019 and accounted for 27.9% of Question 7 funding and 59 projects. **Prevalence Studies**, such as studies under the **Autism and Developmental Disabilities (ADDM) Network**, followed with 13.1% of Question 7 funding (18 projects) in 2019. Funding supporting

2019
Question 7: Infrastructure and Prevalence
Funding by Subcategory

Biobanks
$3,956,796
9.6%
12 projects

Research Workforce
Development
$11,552,632
27.9%
59 projects

Data Tools
$13,069,319
31.6%
25 projects

Research Recruitment
and Clinical Care
$3,298,136
8.0%
20 projects

Research Infrastructure
$4,068,841
9.8%
20 projects

Prevalence Studies
$5,423,000
13.1%
18 projects
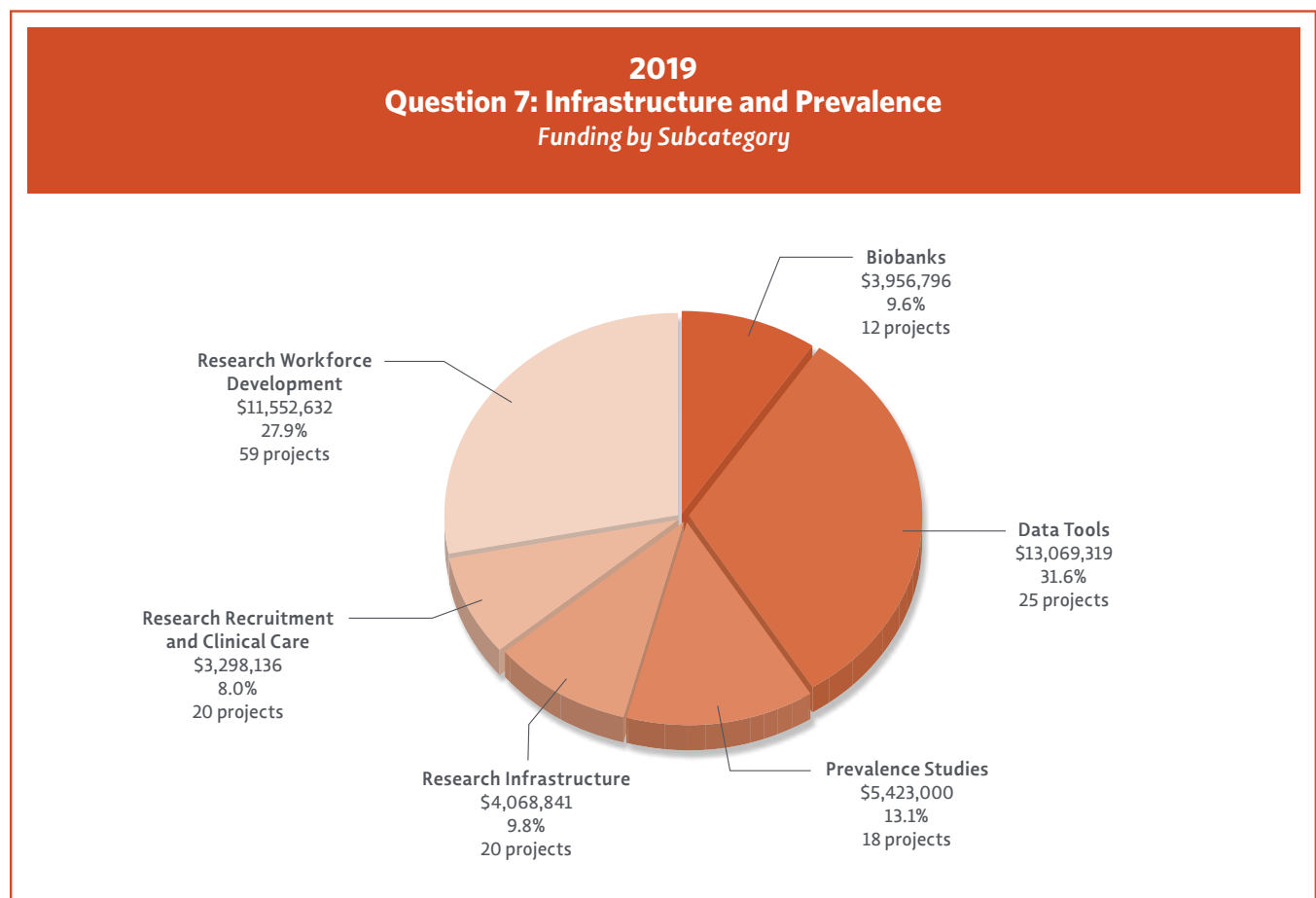
Figure 57. 2019 Question 7 funding by Subcategory.

coordinating centers that analyze data and disseminate research to the community are included within **Research Infrastructure**, which received 9.8% of Question 7 funding in 2019 and supported 20 projects. **Biobanks** received 9.6% of Question 7 funding (12 projects) in 2019, and **Research Recruitment and Clinical Care**, focused on increasing participation in research studies and conducting medical evaluations of participants, received 8.0% of 2019 Question 7 funding with 20 projects. In 2020, Research

Infrastructure received the second largest proportion of Question 7 funding at 18.7% and 18 projects. This was followed by Prevalence Studies, which received 16.6% of Question 7 funding for 11 projects. Research Recruitment and Clinical Care received 13.6% of 2020 Question 7 funding (22 projects), and Research Workforce Development received 12.4% of funding with 51 projects. Biobanks received 7.6% of Question 7 funding in 2020 with 16 projects.

2020
Question 7: Infrastructure and Prevalence
Funding by Subcategory

Biobanks
$2,748,372
7.6%
16 projects

Research Workforce Development
$4,489,396
12.4%
51 projects

Research Recruitment and Clinical Care
$4,919,187
13.6%
22 projects

Data Tools
$11,299,531
31.1%
25 projects

Research Infrastructure
$6,795,151
18.7%
18 projects

Prevalence Studies
$6,041,899
16.6%
11 projects
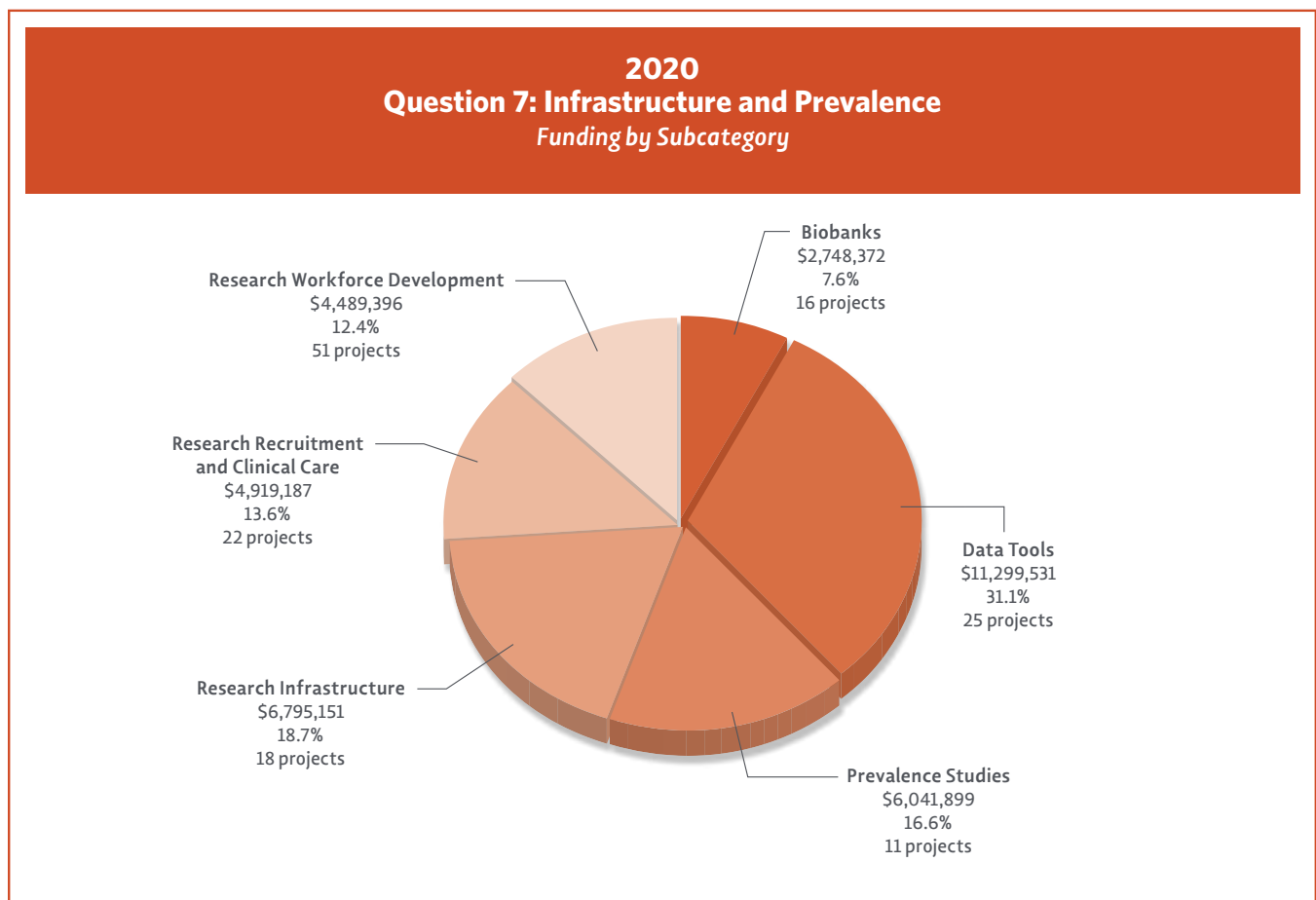
Figure 58. 2020 Question 7 funding by Subcategory.

QUESTION 7 FUNDING OVER TIME: 2008-2020

Figure 59 shows the trend in Question 7 funding over the 13-year span of 2008-2020. Research within Question 7 experienced a rapid increase in funding from 2008-2010. Funding levels for Infrastructure and Prevalence projects then leveled off from 2010-2014. The year 2015 saw an increase in funding for Question 7 research projects; however, it was followed by a 32.3%

funding decrease in 2016. This decrease is in part attributable to the recoding of some projects from several funders to better align with the new Objectives of the *2016-2017 IACC Strategic Plan.* Funding levels remained relatively stable in between 2016 and 2020, with the exception of a 17.5% increase in 2019.
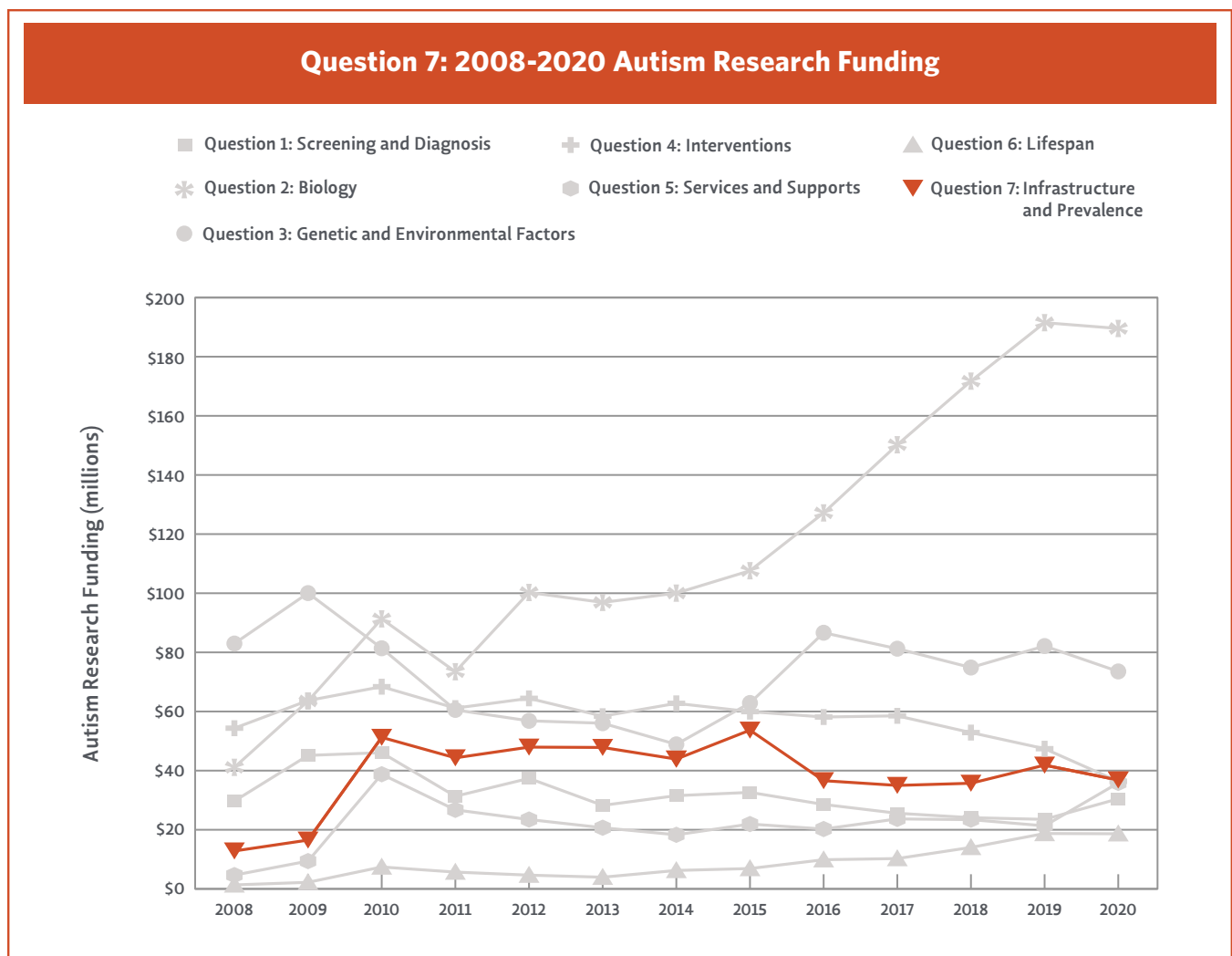
Figure 59. Question 7 autism research funding from 2008-2020. Following an initial increase from 2008-2010, funding for Question 7 remained relatively flat from 2010-2015, followed by a 32.3% decrease in 2016. Funding levels have been relatively stable from 2016 to 2020, except for a 17.5% increase in 2019.

Cross-Cutting Objective: Autism in Girls and Women

In addition to the 22 primary Objectives, the *2016-2017 IACC Strategic Plan* includes a **Cross-Cutting Objective** on the topic of autism in girls and women: "Support research to understand the underlying biology of sex differences in autism, possible factors that may be contributing to underdiagnosis, unique challenges that may be faced by girls/women on the autism spectrum, and develop strategies for meeting the needs of this population." Individual projects assigned to this Objective are also coded to one of the 22 primary Objectives of the Strategic Plan, depending on which aspect of autism in girls and women is being studied. This ensures that the funding associated with those projects will be counted toward the totals of their respective Questions and also allows the projects to be analyzed together under a single Objective. It is important to note that many of the projects in the broader portfolio include women/girls as part of their overall approach; the goal of a "Cross-Cutting" Objective on girls and women with autism is to identify and track projects that specifically address this population. Examples of these projects are those that focus on the underlying biology of autism in girls/women (differences in brain structure, function,

physiology); development of strategies to meet the intervention, service, and support needs of girls/women with autism; identification of genetic and environmental factors that contribute to sex differences; and projects that develop, adapt, or validate screening and diagnostic tools to detect autism in girls and women.

In 2019, the amount of funding specifically devoted to the Cross-Cutting Objective on autism in girls and women totaled $7.0 million (1.6% of total funding) and spanned 32 projects. **Figure 60** shows the proportion of funding focused on autism in girls and women dedicated to each Question area for 2019. The bulk of projects that fell under this Cross-Cutting Objective addressed the underlying Biology of sex differences in autism (Question 2), accounting for 70.4% of the funding ($4.9 million, 20 projects) devoted to this topic. Question 3 (Genetic and Environmental Factors) accounted for 27.2% of funding ($1.9 million, 9 projects). This was followed by Question 5 (Services and Supports, 1.4%, $100,000, 1 project) and Question 6 (Lifespan, <1%, $64,200, 1 project). Question 1 (Screening and Diagnosis) had one active project, which did not receive any funding in 2019, specifically addressing autism in girls and women.
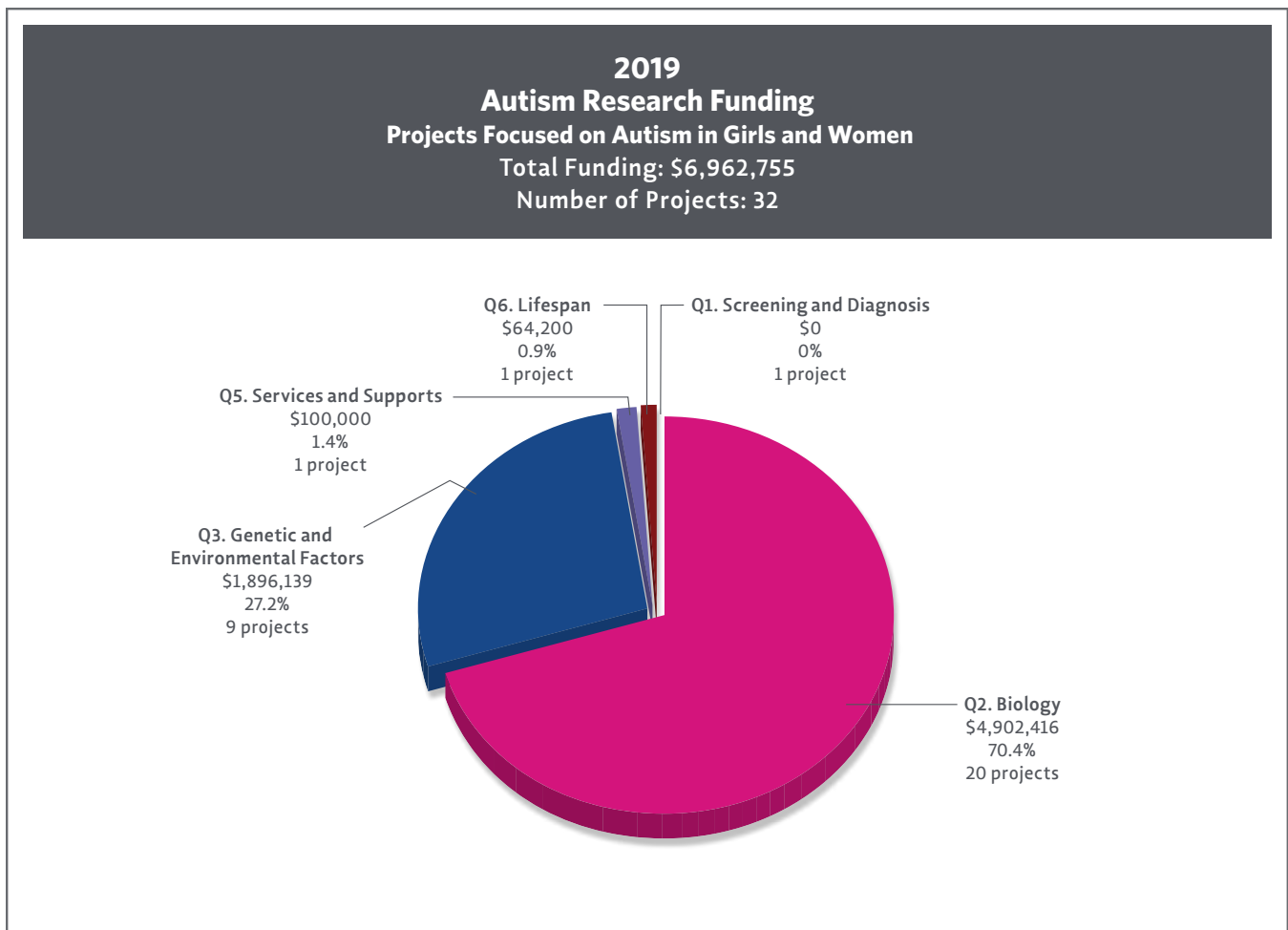
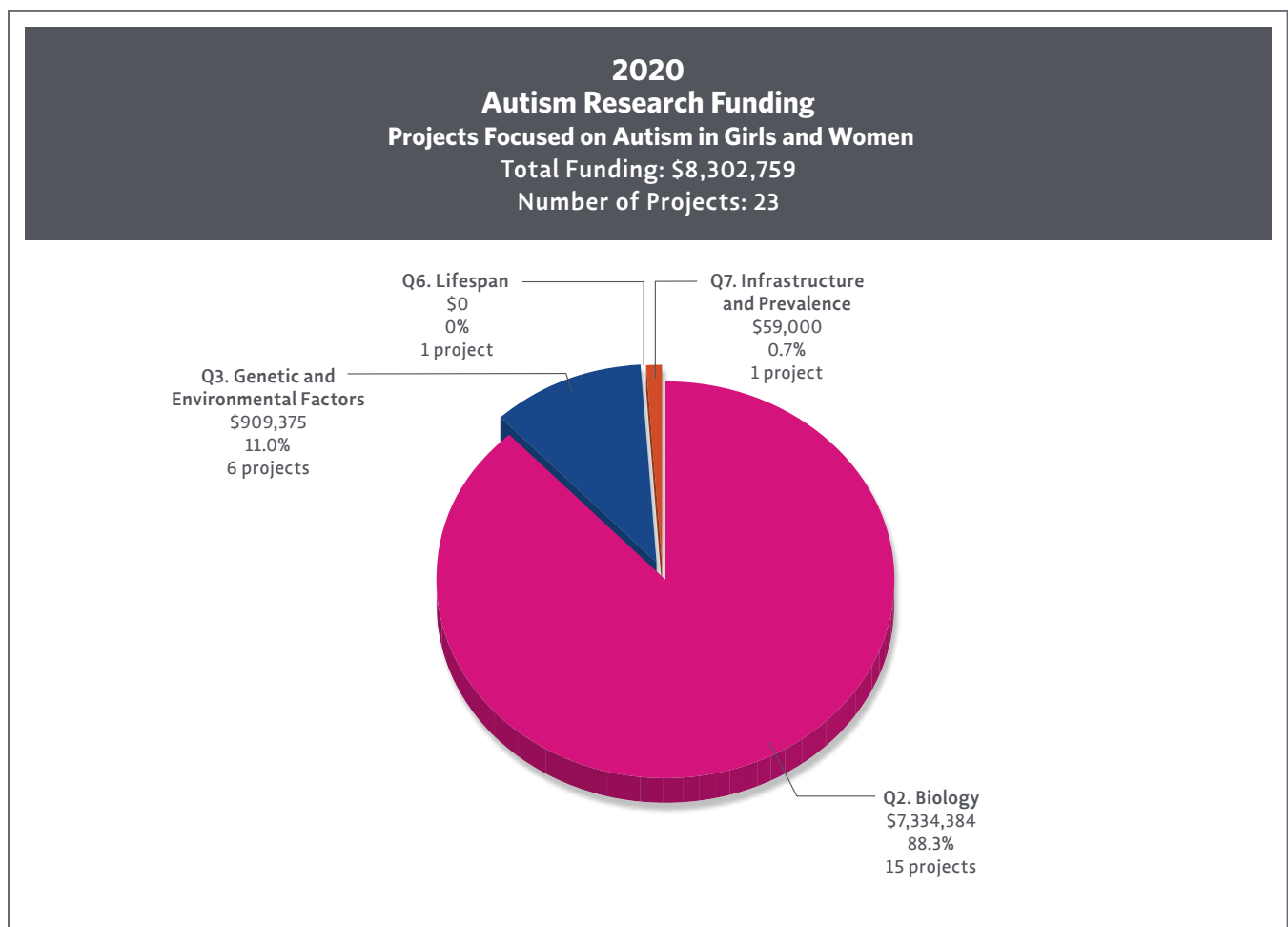**Figure 60.** 2019 autism research funding specifically focused on autism in girls and women by IACC Strategic Plan Question.

In 2020, $8.3 million (23 projects, 2.0% of total funding) specifically addressed the Cross-Cutting Objective on autism in girls and women. When comparing how funding focused on autism in girls and women is divided among the Strategic Plan Question areas in 2020, Question 2 (Biology) accounted for 88.3% ($7.3 million, 15 projects) of total funding for the Cross-Cutting Objective (**Figure 61**). Question 3 (Genetic and Environmental Factors) accounted for 11.0% of funding ($909,375; 6 projects), and Question 7 (Infrastructure and Prevalence) accounted

for less than 1% of funding ($59,000, 1 project). Question 6 (Lifespan) had one active project focused on autism in girls and women that did not receive any funding in 2020. Question 1 (Screening and Diagnosis), Question 4 (Interventions), and Question 5 (Services) did not have any projects in 2020 that specifically addressed the Cross-Cutting Objective. While no projects in 2020 addressed screening and diagnosis, interventions, or services targeted specifically for girls and women with autism, the IACC will monitor these areas in future reports.

2020
Autism Research Funding
Projects Focused on Autism in Girls and Women
Total Funding: $8,302,759
Number of Projects: 23

Q6. Lifespan
$0
0%
1 project

Q7. Infrastructure
and Prevalence
$59,000
0.7%
1 project

Q3. Genetic and
Environmental Factors
$909,375
11.0%
6 projects

Q2. Biology
$7,334,384
88.3%
15 projects

Figure 61. 2020 autism research funding specifically focused on autism in girls and women by IACC Strategic Plan Question.

Cross-Cutting Theme: Disparities in Autism

Research demonstrates significant ongoing racial, ethnic, socioeconomic, and geographic disparities that are experienced by people within the autism community. These are evident in areas such as rates and age of diagnosis, access to and utilization of services, and implementation and availability of culturally and linguistically appropriate evidence-based interventions. To gain a better understanding of the amount of U.S. research funding that is directed towards addressing these disparities, an analysis of all projects within the 2019-2020 autism research portfolio was conducted.[5] Individual projects assigned to this **Cross-Cutting Theme** are also coded to one of the 22 primary Objectives of the Strategic Plan, depending on what type of disparity is being studied. This ensures that the funding associated with those projects will be counted toward the totals of their respective Questions while allowing the projects to be analyzed together under a single Theme.[6]

This analysis provides an overview of the research funding that was allocated to projects that are focused on addressing racial, ethnic, socioeconomic, and geographic disparities within the autism community. These projects target issues such as racial and ethnic disparities in early diagnosis and access to services and interventions; implementation of evidence-based interventions in under-resourced, high-need settings such as urban public schools and rural health care centers; the relationship between socioeconomic status and autism; and modification of existing autism parent

education and quality improvement programs for use in pediatric practices serving low-income, bilingual Latino communities. Also included were funding for scholarship and training programs that specifically recruit students from underrepresented groups to expand the diversity of the autism scientific and services workforce.

In 2019, $28.0 million in research funding was dedicated to 94 autism projects addressing racial, ethnic, socioeconomic, and geographic disparities. This represents 6.6% of total autism research funding in 2019. **Figure 62** illustrates the proportion of autism disparities research funding that was dedicated to each Question area in 2019. Of the total funding dedicated to projects addressing disparities within the autism community in 2019, Question 5 (Services and Supports) was the category that received the largest proportion of funding (34.5%, $9.6 million, 45 projects). This was followed by Question 3 (Genetic and Environmental Factors, 28.7%, $8.0 million, 7 projects) and Question 7 (Infrastructure and Prevalence, 15.4%, $4.3 million, 11 projects). Question 6 (Lifespan) accounted for 7.6% ($2.1 million, 10 projects) of funding on disparities, while Question 1 on Screening and Diagnosis accounted for 6.9% ($1.9 million, 9 projects) of funding. Lastly, funding for Question 2 (Biology) made up 5.3% of disparities funding ($1.5 million, 4 projects), and 1.5% of funding ($424,442, 8 projects) addressed disparities in Interventions (Question 4).

---

5 Some (but not all) of these projects were categorized under the following relevant *2016-2017 IACC Strategic Plan* Objective Codes: 1.2. Reduce disparities in early detection and access to services; 5.2. Reduce disparities in access and in outcomes for underserved populations.

6 Though the *2016-2017 IACC Strategic Plan* does not include a formal Cross-Cutting Objective on disparities, the Committee began tracking research in this area beginning in the *2017-2018 IACC Portfolio Analysis Report*. The IACC created and added a formal Cross-Cutting Recommendation on diversity, equity, inclusion, and accessibility to the recently published *2021-2023 IACC Strategic Plan*, and future Portfolio Analysis Reports will continue to provide analysis of the funding and number of projects focused on these important topics.
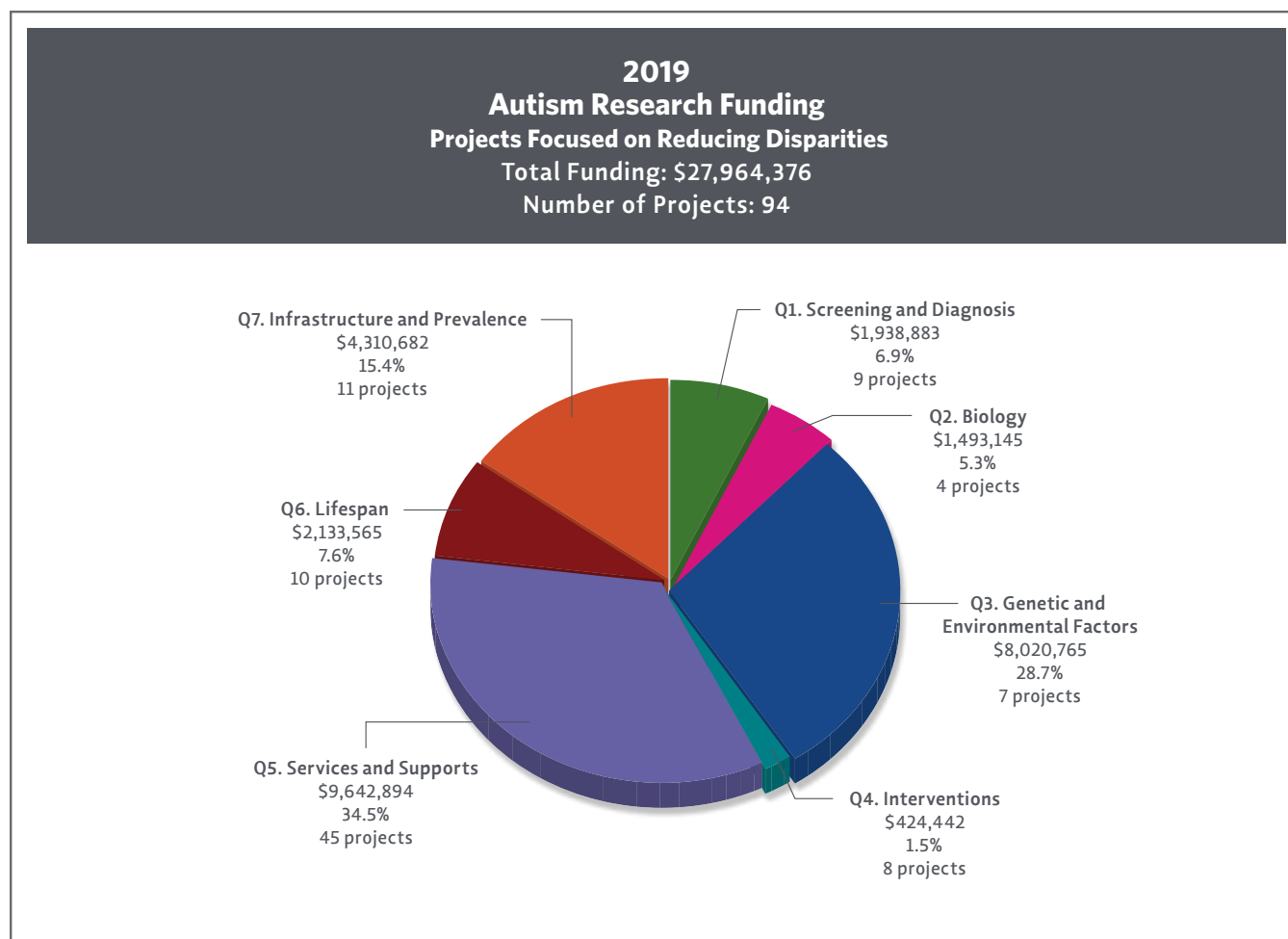
2019
Autism Research Funding
Projects Focused on Reducing Disparities
Total Funding: $27,964,376
Number of Projects: 94

Q7. Infrastructure and Prevalence
$4,310,682
15.4%
11 projects

Q1. Screening and Diagnosis
$1,938,883
6.9%
9 projects

Q2. Biology
$1,493,145
5.3%
4 projects

Q6. Lifespan
$2,133,565
7.6%
10 projects

Q3. Genetic and
Environmental Factors
$8,020,765
28.7%
7 projects

Q5. Services and Supports
$9,642,894
34.5%
45 projects

Q4. Interventions
$424,442
1.5%
8 projects

Figure 62. 2019 autism research funding specifically focused on reducing disparities by IACC Strategic Plan Question.

In 2020, $24.0 million of autism research funding prioritized racial, ethnic, socioeconomic, and geographic disparities, which represented 5.7% of total funding, spanning all seven Questions of the IACC Strategic Plan. While there is a decrease in funding compared to 2019, the number of active projects (94 projects) remained the same, as the funding mechanism for some large projects took the form of a one-time disbursement of funds in 2019 to support research activities for the next several years. In 2020, the proportion of autism disparities funding for each Question area (**Figure 63**) remained relatively consistent with those observed for 2019. Question 5 (Services and Supports) was the category that received the largest proportion of funding (37.4%, $9.0 million, 47 projects). This was followed by Question 3 (Genetic and Environmental Factors, 30.5%, $7.3 million, 5 projects) and Question 1 (Screening and Diagnosis, 14.0%, $3.4 million, 11 projects). Approximately 7.4% of funding ($1.8 million, 10 projects) addressing disparities went to Question 7 (Infrastructure and Prevalence). Question 6 (Lifespan) and Question 2

(Biology) received 5.4% ($1.3 million, 11 projects) and 4.5% ($1.1 million, 5 projects) of the funding dedicated to addressing disparities, respectively, and Question 4 received less than 1% of the disparities funding ($170,317, 5 projects).

Funding data from both years indicate that research focused on disparities has been most concentrated in studies on early detection, services access and delivery, genetic and environmental factors, and diversification of the autism research and services workforce. It is notable that only a small proportion of projects in the highest-funded area of autism research overall, Question 2 (Biology), were specifically focused on understanding disparities. Overall, disparities research is a critically important area, and the IACC Portfolio Analysis Reports will continue to track research funding for autism projects that address racial, ethnic, socioeconomic, and geographic disparities.
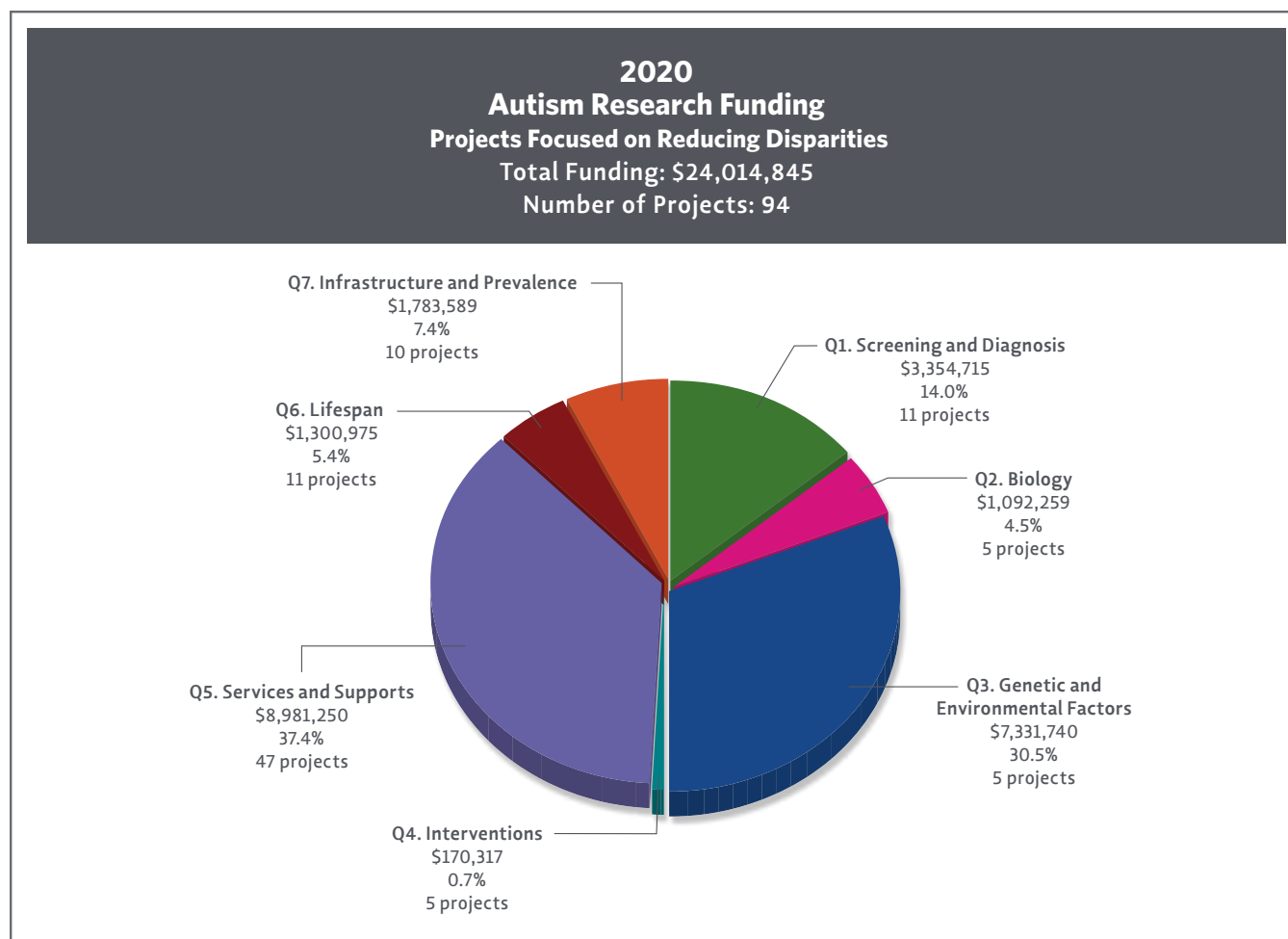
2020
Autism Research Funding
Projects Focused on Reducing Disparities
Total Funding: $24,014,845
Number of Projects: 94

Q7. Infrastructure and Prevalence
$1,783,589
7.4%
10 projects

Q1. Screening and Diagnosis
$3,354,715
14.0%
11 projects

Q6. Lifespan
$1,300,975
5.4%
11 projects

Q2. Biology
$1,092,259
4.5%
5 projects

Q5. Services and Supports
$8,981,250
37.4%
47 projects

**Q3. Genetic and
Environmental Factors**
$7,331,740
30.5%
5 projects

Q4. Interventions
$170,317
0.7%
5 projects

Figure 63. 2020 autism research funding specifically focused on reducing disparities by IACC Strategic Plan Question.

Summary and Conclusion

The *2019-2020 IACC Autism Research Portfolio Analysis Report* represents the 12th and 13th years of data collected and the ninth comprehensive report of U.S. autism research funding across both the federal and private sectors. Project information was collected from 30 federal and private funders; the diverse missions of the different funders are reflected in the autism research portfolio across the seven Questions of the Strategic Plan (**Figures 20-22**). In 2019 and 2020, nine funders were added to the portfolio analysis, providing an updated and more comprehensive view of the autism research funding landscape. While added funders did not have a large impact on overall funding trends, emerging new funders fill in gaps and increase the scope and breadth of autism research. Comparable to previous years, federal agencies funded nearly 83% of autism research while private organizations contributed approximately 17% of funding (**Figures 3** and **4**). Among the participating funders, the National Institutes of Health continued to contribute the largest federal (and overall) investment in autism research, and the Simons Foundation was the largest private funder (**Figures 9** and **10**).

One of the key aims of the Portfolio Analysis Report is to analyze and present information regarding funding addressing the research priorities outlined in the Strategic Plan. This report represents the third analysis to measure research funding against the Objectives of the *2016-2017 IACC Strategic Plan*. Every Objective in the *2016-2017 Strategic Plan* had associated projects and funding in 2019 and 2020, indicating that the priority areas identified by the Committee were also identified and supported as priority areas by federal and private research funders. Each Strategic Plan Question has sustained similar relative proportions of funding since 2010 (**Figures 12-15**). In 2019 and 2020, Question 2 (Biology) continued to be the largest research area funded. Question 3 (Genetic and Environmental Factors) and Question 4 (Interventions) had the next largest amounts of funding, as in previous years. Question 7 (Infrastructure and Prevalence) and Question 1 (Screening and Diagnosis) maintained consistent funding levels as years prior. Lastly, while Question 5 (Services and Supports) and Question 6 (Lifespan) continued to have the smallest amounts of funding, research activity in both Question areas has increased in recent years, as funders have responded to the evolving needs of the autism community and have funded work in alignment with the recommendations made in the IACC Strategic Plan. In particular, Question 5 funding for services-related research grew considerably in 2020 due to new investments by federal and private funders. Funding for Question 6 on topics related to transition-age youth, young adults, and older adults has also approximately doubled since 2016 (**Figures 16** and **17**).

The *2019-2020 IACC Autism Research Portfolio Analysis Report* also includes a comprehensive analysis of the Cross-Cutting Objective on autism in girls and women and an examination of autism projects focused on addressing racial, ethnic, geographic, and socioeconomic disparities, which has been an area of growing interest. Each of these analyses will continue to be tracked in future reports in an effort to understand the autism research landscape and highlight potential gaps.

With 13 years of data available, it was possible to draw meaningful observations about the progress of autism research funding levels from 2008 to 2020 (**Figures 6** and **7**). Autism research showed an overall upward trend in funding, increasing by 88.5% since 2008. Funding for autism research among both federal and private funders totaled $424.2 million and spanned 1,604 projects in 2019. In 2020, total U.S. autism

research funding was estimated to be $418.9 million, spanning 1,573 projects. While this represents a 1.2% decrease in funding compared to 2019, it is a 6.3% increase compared to 2018. Multiple factors may have contributed to fluctuations in funding, including differences in how some funders allocate funding for research projects, shifts in funding priorities, availability of resources, and potential impacts of the COVID-19 pandemic. Additionally, it is important to note that funding in certain areas remained consistent or even increased from 2019 to 2020 (e.g., Lifespan, Services and Supports, Screening and Diagnosis), demonstrating a continued commitment to these topics.

There is great need for continued and expanded research to support the health and well-being of people with autism and their families and caregivers. As described in the Budget Recommendation section of the recently published *2021-2023 IACC Strategic*

Plan for Autism, an infusion of resources in areas such as lifespan issues, evidence-based interventions and services, and research on reducing disparities and increasing equity may help to broaden the scope of autism research to more effectively serve autistic people of all ages, all levels of ability, and in diverse communities across the nation. In the next iteration of the Portfolio Analysis Report, funding levels will continue to be analyzed to highlight trajectories of growth in different topical areas and identify areas in need of increased investment. 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 greatly impact the lives of individuals across the autism spectrum and lifespan.

APPENDICES

APPENDIX A: SUPPLEMENTAL TABLES

Year	Private Funding	Federal Funding	ARRA Funding	Total Funding
2008	$78,490,497	$143,724,845	N/A	$222,215,342
2009	$76,958,649	$173,526,725	$63,900,000	$314,385,374
2010	$74,135,764	$274,541,512	$59,900,000	$408,577,276
2011	$66,758,516	$233,120,629	N/A	$299,879,145
2012	$71,814,178	$260,135,755	N/A	$331,949,933
2013	$72,940,246	$232,639,886	N/A	$305,580,132
2014	$59,356,793	$250,517,114	N/A	$309,873,907
2015	$65,026,914	$277,609,115	N/A	$342,636,029
2016	$72,699,481	$291,735,773	N/A	$364,435,254
2017	$74,126,021	$307,750,413	N/A	$381,876,434
2018	$67,352,634	$326,860,127	N/A	$394,212,761
2019	$74,326,593	$349,875,753	N/A	$424,202,347
2020	$73,073,062	$345,842,322	N/A	$418,915,385

Table 10. Federal and private autism research funding from 2008 to 2020, including supplementary funding provided by the American Recovery and Reinvestment Act (ARRA) in 2009 and 2010.

Strategic Plan Question	Year	Federal	Private
Question 1: Screening and Diagnosis	2019	$20,917,125	$1,960,889
	2020	$27,388,952	$2,507,612
Question 2: Biology	2019	$167,654,187	$24,613,163
	2020	$165,552,455	$24,736,804
Question 3: Genetic and Environmental Factors	2019	$57,942,502	$24,041,016
	2020	$53,850,226	$19,475,869
Question 4: Interventions	2019	$40,426,210	$6,552,181
	2020	$29,763,206	$6,073,684
Question 5: Services and Supports	2019	$18,489,414	$2,180,709
	2020	$30,313,072	$4,990,695
Question 6: Lifespan	2019	$17,065,214	$991,012
	2020	$17,291,396	$677,877
Question 7: Infrastructure and Prevalence	2019	$27,381,101	$13,987,623
	2020	$21,683,015	$14,610,521

Table 11. Federal and private funding amounts for each Question area of the IACC Strategic Plan in 2019 and 2020.

Strategic Plan Question	Year	Specific to Objectives	Core/Other
Question 1: Screening and Diagnosis	2019	$21,882,829	$995,185
	2020	$29,048,232	$848,332
Question 2: Biology	2019	$186,317,244	$5,950,106
	2020	$189,340,601	$948,658
Question 3: Genetic and Environmental Factors	2019	$81,983,518	$0
	2020	$73,153,361	$172,734
Question 4: Interventions	2019	$46,398,497	$579,894
	2020	$35,261,544	$575,346
Question 5: Services and Supports	2019	$19,795,124	$875,000
	2020	$34,278,767	$1,025,000
Question 6: Lifespan	2019	$18,056,126	$100
	2020	$17,969,273	$0
Question 7: Infrastructure and Prevalence	2019	$36,276,966	$5,091,758
	2020	$31,378,726	$4,914,810

Table 12. 2019 and 2020 funding amounts for autism projects assigned to a specific Strategic Plan Objective and for projects designated as Core/Other by Strategic Plan Question area.

APPENDIX B:
FEDERAL AGENCY AND PRIVATE ORGANIZATION DESCRIPTIONS

FEDERAL AGENCIES – DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS)

Administration for Community Living (ACL)

Formed in 2012, ACL serves as the federal agency responsible for increasing access to community supports, while focusing attention and resources on the unique needs of older adults and people with disabilities across the lifespan. ACL awards grants primarily to state and local governments, nonprofit organizations, institutions of higher education, and small businesses. Some are awarded in accordance with formulas (mandatory grants) established in legislation, while others are awarded in a competitive process (discretionary grants). ACL funds the **AutismNOW** web resource hosted by the Arc, which provides information for the autism community on topics including detection, intervention, education, transition from high school into early adulthood, employment, advocacy, community inclusion, aging issues, and public policy.

Agency for Healthcare Research and Quality (AHRQ)

The mission of AHRQ is to produce evidence to make health care safer; higher quality; more accessible, equitable, and affordable; and to work within HHS and with other partners to make sure that the evidence is understood and used. Grant applications submitted to AHRQ undergoes a peer review process, and the Agency decides which applications to fund based on scientific and technical merit, Agency research priorities, and availability of grant funds. AHRQ's autism portfolio includes projects to evaluate the comparative effectiveness of autism interventions and to conduct systematic reviews of the literature on topics such as autism screening and autism interventions, with the goal of evaluating the strength of the evidence supporting practices and identifying gaps in research. AHRQ also funds projects aimed at disseminating information about best practices and other findings from their reviews to researchers, practitioners, the patient community, and other stakeholders.

Centers for Disease Control and Prevention (CDC)

The mission of CDC is to protect America from health, safety and security threats, both foreign and in the U.S. To accomplish this mission, CDC conducts critical science and provides health information that protects the nation against expensive and dangerous health threats, and responds when these arise. CDC awards and administers grants and cooperative agreements to transfer money, technical assistance, and expertise to partners in exchange for their contributions to federal public health goals and objectives. CDC's autism research portfolio includes projects to collect data on autism prevalence, factors that may contribute to autism, and projects to improve awareness, early detection, and intervention. CDC funds the **Autism and Developmental Disabilities (ADDM) Network**, a group of programs that aim to estimate the number of children with autism and other developmental disabilities living in different areas of the United States. CDC also funds the **Study to Explore Early Development (SEED)**, which is currently the largest study in the United States to help identify factors that may increase the probability of autism and other developmental disabilities.

Food and Drug Administration (FDA)

The FDA is responsible for protecting the public health by ensuring the safety, efficacy, and security of human and veterinary drugs, biological products, and medical

devices; and by ensuring the safety of our nation's food supply, cosmetics, and products that emit radiation. The Administration achieves this mission by applying the latest technology and science-based standards to the regulatory challenges presented by drugs, biologics, medical devices, food additives, and tobacco. The FDA supports the **Autism Biomarkers Consortium for Clinical Trials (ABC-CT)** in collaboration with NIH and other funding partners.

Health Resources and Services Administration (HRSA)

HRSA is the primary federal agency for improving access to health care services for people who are uninsured, isolated, or medically vulnerable. HRSA fulfills its mission through grants and cooperative agreements. Applications submitted to HRSA undergo technical review by a panel of independent experts, and HRSA determines who will receive awards based on input from the technical review and ensures that the projects are financially viable and comply with program requirements. The Maternal and Child Health Bureau (MCHB) supports autism-related programs through the Autism CARES Act of 2019, including projects to increase awareness, reduce barriers to screening and diagnosis, promote the development of guidelines for evidence-based practices, and train health care professionals to provide screening as well as diagnostic and early, evidence-based intervention. Flagship programs include the **Autism Intervention Research Networks** (**AIR-B** and **AIR-P**), the **Developmental Behavioral Pediatrics Research Network** (**DBPNet**), and the **Leadership Education in Neurodevelopmental and Related Disabilities (LEND)** program.

National Institutes of Health (NIH)

The NIH is the nation's medical research agency and works to turn scientific discoveries into better health for all. NIH provides financial support for research and research-related activities in the form of grants, cooperative agreements, and contracts. Applications

for funding are assigned to an NIH Institute or Center (IC) and a scientific review group for evaluation of scientific and technical merit. Applications undergo a rigorous two-stage review carried out by non-federal scientists, followed by Advisory Councils or Boards. Following review of all applicable information, the IC considers the score given to an application during the peer review process, the IC's portfolio balance, public health needs, programmatic relevance, IC priorities, requirements specified in congressional appropriations, and availability of funds to determine which applications are funded. NIH supports a broad range of research on autism, including projects on the basic neuroscience of autism, genetic and environmental factors, diagnosis, interventions, and services research. One of NIH's flagship autism programs, the **Autism Centers of Excellence (ACE) Program**, funds a collection of research centers and networks across the country that conduct research on autism. To support and accelerate research on the biology underlying autism and effective interventions for autistic individuals, NIH created the National Database for Autism Research (NDAR) as an informatics system and central repository for data from people on the autism spectrum. Beginning in 2020, data that were previously stored in NDAR, as well as new data from autism studies, are now incorporated in the **National Institute of Mental Health Data Archive (NDA)**.

OTHER FEDERAL DEAPRTMENTS AND AGENCIES

Defense Advanced Research Projects Agency (DARPA)

DARPA's mission is to make pivotal investments in breakthrough technologies for national security. DARPA pursues opportunities for transformational, rather than incremental, change in collaboration with academic, corporate, and government partners. Program managers, individuals at the top of their field

from academia, industry, and government agencies, are invited to DARPA for three-to-five-year terms to run programs with ambitious goals and high-level vision, funding researchers in academia and across industry. DARPA recently funded a project using artificial intelligence to validate biomarkers for autism.

Department of Defense – Army (DoD – Army)

The DoD is charged with coordinating and supervising all agencies and functions of the government directly concerned with national security and the U.S. Armed Forces. Within the DoD's Army Defense Health Research Program, the **Congressionally Directed Medical Research Program (CDMRP) Autism Research Program (ARP)** was established in 2007, with the mission to improve the lives of individuals with autism by promoting innovative research that advances the understanding of autism and leads to improved outcomes for those on the autism spectrum. The projects that the ARP funds span the scope of the IACC Strategic Plan. In addition, other CDMRP Research Programs such as the **Neurofibromatosis Research Program (NFRP)** and the **Tuberous Sclerosis Complex Research Program (TSCRP)** also fund research projects relevant to autism. CDMRP applications undergo both peer and programmatic review to ensure scientific excellence and programmatic relevance. Review panels are made up of scientists, clinicians, consumers from advocacy communities, members of the military, and other specialists as applicable to the award mechanism and program area. Consumers on the review panel play a major role in ensuring that the research is relevant and has the potential to make a significant impact on the affected community.

Department of Education (ED)

The mission of ED is to promote student achievement by fostering educational excellence and ensuring equal access. ED offers both discretionary grants awarded in a competitive process and formula grants which use formulas determined by Congress and has no

application process. For funding opportunities through ED's Institute for Education Sciences, applications undergo a peer review process similar to that of NIH before funding decisions are made. The Department funds a portfolio of autism-related projects concerning the development and delivery of educational interventions and services, particularly for children and transition-age youth. A large portion of ED's funding goes towards developing practitioner training as well as investment in training researchers.

Environmental Protection Agency (EPA)

The mission of the EPA is to protect human health and the environment. EPA co-funds the **Center for Children's Environmental Health (CCEH)** at the University of California, Davis with the National Institute of Environmental Health Sciences, NIH, which conducts research into how environmental exposure to toxins might interact with a person's genes and immune system to influence the probability and characteristics of autism. Applications for EPA funding opportunities go through a rigorous peer review by a panel of external experts in the applicable fields of study. Grant applications that receive high scores from the peer review then undergo an internal programmatic review involving program experts from the EPA. Following these reviews, EPA's National Center for Environmental Research Director will determine what applications will be recommended for funding.

Institute of Museum and Library Services (IMLS)

The mission of IMLS is to advance, support, and empower America's museums, libraries, and related organizations through grantmaking, research, and policy development. IMLS funds research grants to develop services that aim make libraries and museums more accessible for autistic individuals. All proposals submitted for IMLS competitive awards are reviewed by library and museum professionals who know the needs of communities, can share promising practices, and are well versed in the issues and concerns of museums and libraries.

National Endowment for the Arts (NEA)

The NEA is an independent federal agency and the largest funder of the arts and arts education in communities nationwide and a catalyst of public and private support for the arts. One of the core functions of the NEA is funding research into the value and impact of the arts. NEA's autism research portfolio includes projects on the use of art to advance health and well-being for autistic individuals, such as through arts-based interventions, and on how the arts can be used to prepare individuals on the autism spectrum for employment. Proposals for funding submitted to the NEA are reviewed by a panel of individuals who represent a broad range of artistic and cultural viewpoints, as well as wide geographic and ethnic diversity, to provide advice about the artistic excellence and artistic merit of proposals in a variety of funding categories.

National Science Foundation (NSF)

NSF is an independent federal agency, formed by Congress to promote the progress of science and to advance the national health, prosperity, and welfare. NSF funds basic research in biology, mathematics, computer science, and the social sciences as well as technology development, but it does not focus on health or disease-related research. Applications submitted to NSF undergo peer review by external expert reviewers. The NSF Program Officer then reviews the proposal and input from reviewers and make recommendations for funding based on various factors, including significance, potential to be transformational for a field, capacity for building a new and promising area of research, or achievement of specific program goals. Although NSF does not have a program focused on autism, it funds several projects that involve basic science or technologies with the potential to be applied to autism in the future. NSF is a leading funder of projects involving technological interventions and supports, including artificial intelligence, robotics, and virtual reality technologies that could be used to enhance daily living skills and activities of individuals with disabilities.

Social Security Administration (SSA)

The mission of the SSA is to advance the economic security of the nation's people through compassionate and vigilant leadership in shaping and managing America's Social Security programs. SSA funds research on retirement and disability for undergraduate students, graduate students, and recent PhD recipients. While SSA does not have an autism-specific program, the Administration funds research on employment for individuals on the autism spectrum through its disability research programs.

PRIVATE ORGANIZATIONS

Autism Research Institute (ARI)

ARI's mission is to meet the needs of the global autism community through research, networking, education, and support for families and people of all ages on the autism spectrum. ARI is dedicated to developing a standard of care for individuals with autism and their families and funds a range of research with a particular emphasis on investigation of the biological underpinnings of autism, including immune and metabolic pathways.

Autism Science Foundation (ASF)

ASF's mission is to support autism research by providing funding and other assistance to scientists and organizations conducting, facilitating, publicizing, and disseminating autism research. The organization also provides information about autism to the general public and serves to increase awareness of autism spectrum disorders and the needs of individuals and families affected by autism. ASF funds the **Autism Sisters Project**, which recruits unaffected sisters of individuals with autism to help researchers understand the female protective effect. ASF also supports the **Baby Siblings Research Consortium**, a network of researchers studying the earliest behavioral and biological features of autism. In addition, ASF funds pre- and postdoctoral

trainees to conduct basic and clinical research relevant to autism, including studies focused on a wide range of topics such as identification of biomarkers, molecular and cellular mechanisms, genetic and environmental factors, interventions, and service delivery.

Autism Speaks (AS)

Autism Speaks is the world's largest autism science and advocacy organization, dedicated to promoting solutions, across the spectrum and throughout the lifespan, for the needs of individuals with autism and their families through advocacy and support; increasing understanding and acceptance of people with autism; and advancing research into causes and better interventions for autism and related conditions. Autism Speaks funds a broad profile of autism research ranging from basic neuroscience and the molecular causes of autism to implementation and testing of interventions for those diagnosed with autism. Autism Speaks supports the **Autism Care Network**, which connects families, researchers, and health care teams across the United States and Canada to continuously improve person- and family-centered autism care. Autism Speaks also collaborates with Google and the wider research community to create **MSSNG**, the world's largest genomic database on autism, with the goal of providing the best resources to enable identification of autism subtypes and provide better diagnostics and more personalized interventions.

BRAIN Foundation (BRAIN)

The mission of the BRAIN Foundation is to support translational research that will lead to the development of FDA-approved treatments and improved standard of care for co-occurring conditions in individuals with autism. The BRAIN Foundation's research portfolio includes funding for research to develop biomarkers, study immunity and gut dysfunction in autism, understand cellular-level differences that contribute to autism, and conduct clinical treatment trials, as well

as initiatives that seek to increase access to care and bridge the gap between research, clinical care, and technology through outreach physician programs.

Brain and Behavior Research Foundation (BBRF)

BBRF is the nation's top non-governmental funder of mental health research grants and funds basic neuroscience research to elucidate the molecular mechanisms underlying brain disorders and conditions. BBRF's autism research portfolio primarily includes studies on the genetics and molecular mechanisms underlying autism.

Eagles Autism Foundation (Eagles)

The Eagles Autism Foundation supports the highest quality and most impactful autism research and care to improve the lives of individuals with autism and their families and foster the acquisition of knowledge, technologies, and discoveries that will bring new opportunities in the future. The Foundation's research portfolio includes research on screening and diagnosis, the biology underlying autism and co-occurring conditions, genetic and environmental factors that may contribute to autism, interventions, and services.

Els for Autism Foundation (ELS)

The Els for Autism Foundation is committed to better understanding the aspirations of people with autism and helping them reach their full potential through better understanding of autism and facilitating the development and delivery of treatment therapies, educational, training, recreational, and independent living programs; developing global outreach to facilitate the sharing of best practices and programs; and raising awareness and promoting the value, acceptance, and inclusion of people with autism. The Foundation's research portfolio includes studies to improve diagnostic tools, better understand the biology of autism and the genetic and environmental factors that contribute to development of autism, and improve interventions and services.

Escher Fund for Autism/Escher Family Fund (EFA)

The Escher Fund for Autism is a donor advised fund at Schwab Charitable. Together with sister fund the Escher Family Fund of Silicon Valley Community Foundation, it promotes science education and spearheads research projects to examine disruptive germline programming and gametic effects of drug, smoking, and chemical exposures, with an emphasis on risk for ensuing abnormal neurodevelopment in offspring.

FRAXA Research Foundation (FRAXA)

FRAXA's mission is to find effective treatments and ultimately a cure for Fragile X syndrome. The Foundation directly funds research grants and fellowships at top universities around the world. It partners with biomedical and pharmaceutical companies, large and small, to bridge the gap between research discoveries and actual treatments. Fragile X syndrome is the leading known single gene cause of autism, and FRAXA funds research projects that are related to understanding autistic features in Fragile X.

New England Center for Children (NECC)

NECC is a private, nonprofit autism research and education center dedicated to transforming the lives of children with autism worldwide through education, research, and technology. NECC strives to be a global leader in the provision of effective, evidence-based educational services for the millions of underserved children with autism and their families.

New Jersey Governor's Council for Medical Research and Treatment of Autism (NJGCA)

NJGCA was created by state appropriation in 1999 and has been issuing research, clinical, and educational enhancement grants since 2000. The Council's vision is to enhance the lives of individuals with autism across their lifespans. The mission of the Council is to advance and disseminate the understanding, treatment, and management of autism by means of a coordinated program of biomedical research, clinical innovation, and professional training in New Jersey.

Organization for Autism Research (OAR)

The mission of OAR is to support research that directly impacts the day-to-day quality of life of those with autism. This includes research to inform and improve education, communication, self-care, social skills, employment, behavior, and adult and community living. In this context, it extends to issues related to family support, the efficacy of service delivery systems, and demographic analyses of the autism community.

Patient-Centered Outcomes Research Institute (PCORI)

PCORI helps people make informed health care decisions and improves health care delivery and outcomes by producing and promoting high-integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader health care community. PCORI's research portfolio primarily includes studies on improving services, including in educational settings, for children, transition-age youth, and adults on the autism spectrum and their families.

Simons Foundation (SF)/Simons Foundation Autism Research Initiative (SFARI)

The mission of Simons Foundation is to advance the frontiers of research in mathematics and the basic sciences. Simons Foundation's single largest initiative is SFARI, which seeks to improve the diagnosis and treatment of autism by funding, catalyzing, and driving innovative research of the greatest quality and relevance. The Simons Foundation autism portfolio includes research on genetic and cellular factors underlying autism, identification of genetic and environmental factors that contribute to autism, and development of potential treatments. Simons Foundation supports the **Simons Simplex Collection**, **SPARK** for autism, and **Autism BrainNet**, three major programs that conduct research and provide important research resources for the autism community.

Thrasher Research Fund (Thrasher)

The Thrasher Research Fund provides grants for clinical, hypothesis-driven research that offer substantial promise for meaningful advances in the prevention, diagnosis, and treatment of children's diseases, particularly research that offers broad-based applications. The Fund provides support for studies to improve medical interventions for autism and co-occurring conditions.

Tuberous Sclerosis Alliance (TSCA)

TSCA is dedicated to finding a cure for tuberous sclerosis complex (TSC), while improving the lives of those affected. Serving as a leader in the rare disease community, TSCA's goals are to accelerate research, improve access and quality of care, support and empower constituents, educate and mobilize to increase investment, and build and strengthen organization. An estimated 40-50% of individuals with TSC have autism, and TSC is a leading genetic cause of syndromic autism. TSCA funds research that focuses on the connection between autism and TSC.

APPENDIX C:
SUBCATEGORY DEFINITIONS

Question 1:
SCREENING AND DIAGNOSIS

Diagnostic and Screening Tools

This Subcategory includes projects that are developing new autism diagnostic and screening tests, as well as those establishing the usefulness of new or revised assessments for autism symptoms. It also encompasses projects aimed at improving early identification services and adapting clinical assessments into other languages for use in multi-lingual community settings and countries in addition to the United States.

Early Signs and Biomarkers

Projects which use a variety of methods to search for signs of autism in very young children (generally under age 3) that could be used for diagnosis, such as eye-tracking, physiological measures, and autism-specific behavioral patterns are included in this Subcategory. More examples include projects investigating metabolic measures, such as the levels of specific chemicals, hormones, or proteins in the blood that could be used as biomarkers of the disorder.

Phenotypes/Subgroups

Included in this Subcategory are projects aimed at identifying distinct subgroups of people with autism, or those that share common morphological, physiological, or behavioral features. Projects in this Subcategory use a variety of methods to identify and distinguish these groups.

Spectrum of Characteristics

These projects seek to define the broad range of autism characteristics, including both biological and behavioral features. Among these studies are some that examine how children and adults with autism vary in their development of social communication, language, cognitive ability, sensory sensitivities, and executive functioning ability. Other projects seek to understand how differences in neurocognitive development can contribute to phenotypic variability in those with an autism diagnosis. In previous editions of the Portfolio Analysis Report, this Subcategory was named "Symptomology." There were no changes made to the inclusion criteria for this Subcategory.

Question 2:
BIOLOGY

Cognitive Studies

These are studies of psychological and mental processes, including memory, producing and understanding language, solving problems, and making decisions. Projects in this Subcategory consist of those that investigate theory of mind, social cognition, emotion regulation, and recall and memory.

Computational Science

Computational methods and modeling allow for the synthesis and study of large and complex sets of data. Some projects in this Subcategory collect extensive experimental biological and behavioral data and use powerful computing techniques to reveal new insights. Other aspects of computer science are also included, such as developing statistical modeling techniques to better understand the biology of autism.

Co-Occurring Conditions

Research on physical and mental health conditions that often co-occur with autism is included here, such as seizures/epilepsy, sleep disorders, gastrointestinal dysfunction, autoimmune disorders, attention deficit hyperactivity disorder (ADHD), anxiety, depression, and suicidality.

Developmental Trajectory

Projects in this Subcategory often include longitudinal studies following various aspects of biological and behavioral development in the same individuals over time. Examples include brain growth, face processing, change in neural connectivity over time, and development of communication skills and language processing. These studies often compare children with autism to their unaffected siblings or other typically developing children.

Immune/Metabolic Pathways

These projects focus on understanding the biological mechanisms of metabolism and the immune system that may be altered in autism, typically using cell cultures and animal models. This largely includes studies on inflammation and inflammatory molecules (i.e., cytokines), as well as on the role of the mitochondria, energy metabolism, and oxidative stress. Also included in this group are projects seeking to identify specific immune and metabolic triggers in early prenatal and post-natal life, such as maternal infection, maternal auto-antibodies, and environmental exposures.

Molecular Pathways

This Subcategory includes studies on specific molecules and proteins (other than the immune and metabolic systems) that may be involved in the development of autism and related genetic disorders (e.g., fragile X syndrome and Rett syndrome). Many of these projects use animal and cellular models to explore the biological effects of specific candidate genes and to identify common molecular pathways, including alterations in synaptic functioning and intracellular signaling cascades.

Neural Systems

Studies in this Subcategory explore the structure and activity of the brain and underlying neural systems involved in autism, including functional connections between brain regions. Many projects seek to identify the precise neural networks and circuits underlying communication and language processing, social interactions, and behavioral issues. These studies frequently employ imaging techniques, such as functional magnetic resonance imaging (fMRI) and diffusion tensor imaging (DTI), and other physiological measures of brain activity, such as electroencephalography (EEG).

Neuropathology

These projects typically include post-mortem examination of brain tissue from individuals with autism. Many of the studies in this Subcategory explore how the architecture of the brain may be altered in individuals with autism or how gene expression varies in different areas of the brain.

Sensory and Motor Function

Projects in this Subcategory explore the neural underpinnings of motor skills and abilities in children with autism and assess visual, auditory, and other sensory processes in the brain.

Subgroups/Biosignatures

Because there is so much heterogeneity among individuals with autism, research to understand how certain subgroups of individuals that share certain behavioral or biological characteristics could help clarify some of the underlying biology in autism. This can be done by searching for certain biological factors ("signatures"), such as patterns of gene expression, hormone levels, or structural differences in the brain, that define a particular subgroup. Many of these projects try to make the connection between certain genes with a known or suspected link to autism and the observable characteristic, or phenotype, that they cause.

Question 3:
GENETIC AND ENVIRONMENTAL FACTORS

Environmental Factors

This Subcategory includes projects investigating environmental factors that may contribute to the development of autism. Examples include studies of how changes of the microbiome, environmental exposures, assistive reproductive treatments, paternal factors, and maternal factors (such as diet, medications taken during pregnancy or to induce labor, perinatal conditions, child and maternal response to immune challenge) may contribute to autism, and registries where many of these factors can be tracked simultaneously.

Epigenetics

Epigenetics is the study of how changes in behaviors, physiology, and/or the environment (including paternal and maternal factors) can affect gene activity without changes in DNA sequence. Unlike genetic changes, which change the actual sequence of nucleotides in DNA, epigenetic changes can modify how DNA sequences are read and how genes are expressed (such as through methylation of DNA). These changes can be transient and reversible, or they may be heritable in some circumstances. Projects in this Subcategory seek to identify some of the influences that may lead to these epigenetic changes and how these epigenetic changes may contribute to autism development.

Gene-Environment

These studies include efforts to identify and understand how the interactions of environmental factors (including paternal and maternal factors), genetic susceptibility, and/or human physiology (e.g., the immune system, metabolic processes) may contribute to the development of autism. (Note: While epigenetic studies are a subset of gene-environment studies, they are tracked as a separate Subcategory because there is a substantial number of these projects, and the topic of epigenetics is of significant public interest.)

Genetic Factors

Projects in this Subcategory seek to identify new genes that are implicated in increased probability of autism or to better understand genetic factors that were previously identified.

Question 4:
INTERVENTIONS

Behavioral

Projects in this Subcategory involve a wide array of behavioral research and training methods, including applied behavior analysis (ABA), naturalistic developmental behavioral interventions (NDBI), cognitive-behavioral therapy, discrete trial training, Early Start Denver Model, imitation training, joint attention training, Lovaas method, pivotal response training, sibling-mediated interventions, and social skills training.

Complementary, Dietary, and Alternative

This Subcategory includes research on acupressure; acupuncture; antioxidants; use of dietary and nutritional supplements, vitamins, and minerals; probiotics; and special diets (e.g., gluten-free, casein-free).

Educational

Nearly all research in classroom settings falls under this Subcategory, including curricula, educational best practices, inclusive education programs, math and reading training, positive behavioral supports, special education programs, TEACCH (Treatment and Education of Autistic and Related Communication-Handicapped Children), and the "Social Stories" approach.

Medical/Pharmacologic

This Subcategory includes research on drugs (e.g., antidepressants, anticonvulsants, antipsychotics, anxiolytics, melatonin, and stimulants) to treat autism and its co-occurring conditions, as well as medical therapies such as transcranial magnetic stimulation (TMS).

Model Systems/Therapeutic Targets

Animal models of autism and those that are being used to develop or test new drug treatments, as well as cell lines used to discover new drug targets or to screen potential drug candidates, are included in this Subcategory.

Occupational, Physical, and Sensory-Based

Therapies in this Subcategory encompass art therapy, motor training (including fine motor skills such as handwriting as well as gross motor training involving balance and posture), music therapy, occupational therapy, pet (animal) therapy, physical activity plans and exercise therapy (bike riding, swimming), physical therapy, sensory integration, therapeutic horseback riding, training in self-care and daily living skills, and vocational rehabilitation.

Technology-Based

Augmentative and alternative communication (AAC), computer applications and software, picture exchange communication system (PECS), social robots, interventions delivered via telehealth and online platforms, video modeling and virtual reality (including virtual and 3D environments to mimic social situations), and wearable sensors are all examples of the types of technology in the projects in this Subcategory.
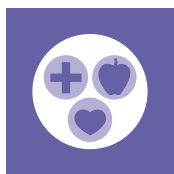
Question 5:
SERVICES AND SUPPORTS

Community Inclusion Programs

These programs provide instruction in social, communication, and leisure skills to enable individuals with autism to participate in sports, recreation, and social-integration activities in fully integrated settings and to build successful relationships with others.

Efficacious and Cost-Effective Service Delivery

This Subcategory includes programs involving web-based curricula and interventions as well as telehealth

methodology, all of which could benefit those in underserved areas. Various parent training projects (to deliver a behavioral therapy, for example) using web-based methods such as teleconsultation and video feedback make distributing the training programs cost-effective and accessible across the country. Studies to improve dental care are also in this Subcategory for effective service delivery.

Family Well-Being and Safety

Studies in this Subcategory evaluate issues of caregiver stress and measures of quality of life for individuals with autism and their families, as well as assess programs to help parents navigate the service system after their child receives an autism diagnosis. It also surveys safety issues for those on the autism spectrum, including wandering and bullying.

Practitioner Training

Projects in this Subcategory seek to increase skill levels in service providers, including medical service providers, direct support workers, parents and legal guardians, education staff, and public service workers.

Services Utilization and Access

These projects include surveys of service systems available in different states, evaluations of patterns of medical service use among children with autism, comprehensive online resources for autism services, and specific efforts in several states to coordinate services for people with autism. They also evaluate disparities in diagnosis and service utilization as well as barriers to access for underserved communities.
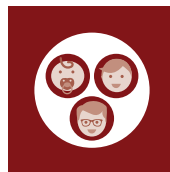
Question 6:
LIFESPAN

Community Integration Supports and Services

This Subcategory includes projects that enhance community services to increase inclusion and develop interventions and supports to improve community involvement among transition-age youth and adults on

the autism spectrum; this Subcategory also includes any sibling and caregiver engagement services and interventions.

Daily Life Skills

Research in this Subcategory focuses on independent living skills instruction (e.g., executive function, self-determination, goal setting) for youth and adults with autism.

Health and Behavioral Outcomes

Projects in this Subcategory focus on understanding and improving health-related outcomes for youth and adults, including interventions for autism and co-occurring conditions, behavioral outcomes, and other longitudinal studies.

Health Care Systems/Health Care Transitions

These projects are focused on efforts to improve provider-patient experiences and interactions across the lifespan; this category includes screening and diagnostic tools focused on youth and adults (not solely autism-specific tools).

Transition to Adulthood and Postsecondary Outcomes

These projects focus on services, tools, and interventions that are helpful to youth making the transition out of high school. Often, these focus on education and employment. This Subcategory also focuses on young adulthood and projects that support postsecondary outcomes such as college experiences, employment, and quality of life outcomes.
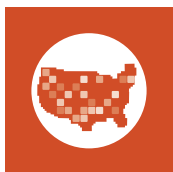
Question 7:
INFRASTRUCTURE AND PREVALENCE

Biobanks

A biobank is a type of biorepository which stores human biological samples for use in research. Projects in this Subcategory support the collection of DNA and tissue samples from autism patients.

Data Tools

These projects include bioinformatics databases to store genetic, phenotypic, and other medical information from autism patients. They also support infrastructure for several of these major databases to interact and dissemination of data to the community and stakeholders.

Prevalence Studies

Research that measures autism prevalence in the United States and internationally is contained in this Subcategory, including the **Autism and Developmental Disabilities Monitoring (ADDM) Network** sites maintained by the CDC.

Research Infrastructure

This Subcategory includes coordinating centers that support multiple research projects by running tests, analyzing data, providing statistical analyses, and disseminating research to the community. These projects also support facilities that operate large, shared instruments used by several scientists to test research samples.

Research Recruitment and Clinical care

Projects in this Subcategory help increase participation in research studies and conduct medical evaluations for the participants, often collecting data that can be used for multiple studies.

Research Workforce Development

Workshops, conferences, and training programs that serve to expand the research workforce, enhance interdisciplinary research training, and recruit early-career scientists into the autism field are included in this Subcategory.

APPENDIX D:
AUTISM-RELATED RESEARCH PROJECTS NOT INCLUDED IN THE IACC PORTFOLIO ANALYSIS

The IACC Portfolio Analysis Reports also include lists of research projects that were identified while conducting the analysis for this report and are related to autism but do not meet the criteria to be considered autism research. These lists include projects that are not exclusively focused on autism but may have implications for autism research in the future or may be helpful in understanding the broader landscape of ongoing research on developmental disabilities, intellectual disabilities, and other topics of relevance to autism. These autism-related project lists have been included as reference materials for community members, researchers, and funders. Please note that these lists are not comprehensive. If you are interested in viewing the list of autism-related research projects for 2019 and 2020, please visit the webpage below.

Direct link to Autism-Related Research Projects: **https://iacc.hhs.gov/publications/portfolio-analysis/2020/asd-related-projects.shtml**

APPENDIX E:
AUTISM RESEARCH DATABASE (ARD)

Detailed information about all projects included in the portfolio analysis since 2008, when the IACC began tracking autism funding in the United States, are available online in the Autism Research Database (ARD). For each project, the ARD includes a short description of the funded project as well as information on the principal investigator and funded institution, the funding institution, amount funded, the award period, and how the project aligns with the IACC Strategic Plan Question and Objectives. In addition, the ARD includes analyses of autism funding by Strategic Plan Questions, Objectives, and Subcategories. Analyses of funding information by funder is also available, as well as a breakdown of federal versus private funding for each year of analysis. Multiyear funding information, broken down by Strategic Plan Objectives, is also provided, along with maps showing where autism research projects are taking place each year. In addition to U.S. funding data, information on autism projects funded by international agencies and organizations is available on the ARD.

Direct link to the Autism Research Database: **https://iacc.hhs.gov/funding/data/**

IACC COMMITTEE MEMBER ROSTER AND ONAC STAFF LIST

Interagency Autism Coordinating Committee Member Roster

CHAIR

Joshua Gordon, M.D., Ph.D.
Director
National Institute of Mental Health
National Institutes of Health
Bethesda, MD

FEDERAL MEMBERS

Monica M. Bertagnolli, M.D.
Director
National Institutes of Health
Bethesda, MD

Diana W. Bianchi, M.D.
Director
Eunice Kennedy Shriver National Institute of Child Health
   and Human Development
National Institutes of Health
Bethesda, MD

Amanda B. Bryans, M.S. (Alternate)
Education and Research to Practice Supervisor
Office of Head Start
Administration for Children and Families
Washington, DC

Anita Everett, M.D., D.F.A.P.A.
Director
Center for Mental Health Services
Substance Abuse and Mental Health
   Services Administration
Rockville, MD

Tiffany R. Farchione, M.D.
Director
Division of Psychiatry
Center for Drug Evaluation and Research
U.S. Food and Drug Administration
Silver Spring, MD

Maria Fryer, M.S.
Program Analyst
Bureau of Justice Assistance
U.S. Department of Justice
Washington, DC

Elaine Cohen Hubal, Ph.D.
Senior Science Advisor
Center for Public Health and Environmental
   Assessment
U.S. Environmental Protection Agency
Research Triangle Park, NC

Jennifer Johnson, Ed.D.
Deputy Commissioner
Administration on Disabilities
Administration for Community Living
Washington, DC

Walter J. Koroshetz, M.D.
Director
National Institute of Neurological Disorders and Stroke
National Institutes of Health
Bethesda, MD

Leah Lozier, Ph.D.
Social Science Analyst
Office of Policy Development and Research
U.S. Department of Housing and Urban Development
Washington, D.C.

Alison R. Marvin, Ph.D.
Statistician/Health Sciences Researcher
Division of the Analytics Center of Excellence
Social Security Administration
Woodlawn, MD

Matthew Miller, Ph.D., M.P.H.
Director
VA Suicide Prevention Program
Office of Mental Health and Suicide Prevention
Veterans Health Administration
U.S. Department of Veterans Affairs
Washington, DC

Kamila Mistry, Ph.D., M.P.H.
Health Scientist Administrator
Associate Director
Office of Extramural Research, Education, and
    Priority Populations
Senior Advisor
Value Based Care Transformation
Child Health and Quality Improvement
Agency for Healthcare Research and Quality
Rockville, MD

Lauren Raskin Ramos, M.P.H.
Director
Division of Maternal and Child Health
    Workforce Development
Maternal and Child Health Bureau
Health Resources and Services Administration
Rockville, MD

Karyl Rattay, M.D., M.S., FAAP
Director
Division of Human Development and Disability
Centers for Disease Control and Prevention
Atlanta, GA

Barbara Roland, M.B.S., LPC (Alternate)
Supervisory Healthcare Administrator
(Mental Health Chief)
Division of Behavioral Health
Office of Clinical and Preventative Services
Indian Health Service
Rockville, MD

Jodie Sumeracki, B.A.
Senior Policy Advisor
Disabled and Elderly Health Programs Group
Centers for Medicare and Medicaid Services
Baltimore, MD

Debara L. Tucci, M.D., M.S., M.B.A., F.A.C.S.
Director
National Institute on Deafness and Other
    Communication Disorders
National Institutes of Health
Bethesda, MD

Larry Wexler, Ed.D.
Director
Research to Practice Division
Office of Special Education Programs
U.S. Department of Education
Washington, DC

Nicole Williams, Ph.D.
Program Manager
Congressionally Directed Medical Research Programs
U.S. Department of Defense
Frederick, MD

Taryn Mackenzie Williams, M.A.
Assistant Secretary
Office of Disability Employment Policy
U.S. Department of Labor
Washington, DC

Richard Woychik, Ph.D.
Director
National Institute of Environmental Health Sciences
Director
National Toxicology Program
National Institutes of Health
Research Triangle Park, NC

PUBLIC MEMBERS

Maria Mercedes Avila, Ph.D., M.S.W., M.Ed.
Associate Professor
Department of Pediatrics
Director
Vermont LEND Program
Larner College of Medicine
University of Vermont
Burlington, VT

Alice Carter, Ph.D.
Professor
Department of Psychology
University of Massachusetts Boston
Boston, MA

Sam Crane, J.D.
Legal Director
Quality Trust for Individuals with Disabilities
Washington, DC

Aisha Dickerson, Ph.D.
Assistant Professor
Department of Epidemiology
Bloomberg School of Public Health
Johns Hopkins University
Baltimore, MD

Thomas Frazier, Ph.D.
Board of Directors
Autism Speaks
Professor of Psychology
John Carroll University
Research Professor
Departments of Pediatrics and Psychiatry
SUNY-Upstate
Cleveland, OH

Dena Gassner, M.S.W.
Ph.D. Candidate in Social Work
Adelphi University
West Hempstead, NY
Adjunct Professor
Department of Health Sciences
Towson University
Towson, MD

Morénike Giwa Onaiwu, Ph.D.
Equity, Justice, and Representation Executive
Committee Chair
Autistic Women & Nonbinary Network
Humanities Scholar
Center for the Study of Women, Gender, and Sexuality
Rice University
Houston, TX

Alycia Halladay, Ph.D.
Chief Science Officer
Autism Science Foundation
New York, NY
Adjunct Faculty
Department of Pharmacology and Toxicology
Rutgers University
Piscataway, NJ

Craig Johnson, M.Ed.
Founder and President
Champions Foundation
Houston, TX

Yetta Myrick, B.A.
Founder and President
DC Autism Parents
Washington, DC

Lindsey Nebeker, B.A.
Marketing Consultant
Independent Contractor
Alexandria, VA

Jenny Mai Phan, Ph.D.
Research Post-Doctoral Fellow
Center for Autism Spectrum Disorders
Children's National Hospital
Washington, DC

JaLynn R. Prince, B.F.A.
Co-Founder, President, and Chair
Madison House Autism Foundation
Rockville, MD

Camille Proctor
Founder
The Color of Autism Foundation
Birmingham, MI

Susan Rivera, Ph.D.
Dean
College of Behavioral & Social Sciences
University of Maryland
College Park, MD

Matthew Siegel, M.D.
Associate Professor of Psychiatry and Pediatrics
Tufts University School of Medicine
Boston, MA
Vice President of Medical Affairs
Developmental Disorders Service Line
Maine Behavioral Healthcare
Westbrook, ME

Ivanova Smith, B.A.
Self-Advocate Faculty
Leadership Education in Neurodevelopmental
	and Related Disabilities
University of Washington
Tacoma, WA

Hari Srinivasan, B.A.
Ph.D. Neuroscience Student and PD Soros Fellow
Vanderbilt University
Nashville, TN

Helen Tager-Flusberg, Ph.D.
Professor
Department of Psychological and Brain Sciences
Director
Center for Autism Research Excellence
Boston University
Boston, MA

Julie Lounds Taylor, Ph.D.
Associate Professor
Department of Pediatrics
Co-Director
University Center for Excellence in
	Developmental Disabilities
Vanderbilt Kennedy Center
Vanderbilt University Medical Center
Nashville, TN

Paul Wang, M.D.
Deputy Director
Clinical Research Associates, LLC
Simons Foundation
New York, NY
Associate Clinical Professor of Pediatrics
Yale University School of Medicine
New Haven, CT

OFFICE OF NATIONAL AUTISM COORDINATION
NATIONAL INSTITUTES OF HEALTH

Office of National Autism Coordination (ONAC)
6001 Executive Boulevard, Bethesda, MD 20892
National Institute of Mental Health
National Institutes of Health
Email: IACCPublicInquiries@mail.nih.gov
Website: https://iacc.hhs.gov/

Office of National Autism Coordination Staff

Susan A. Daniels, Ph.D.
National Autism Coordinator, U.S. Department of Health and Human Services
Director, Office of National Autism Coordination, National Institute of Mental Health
Executive Secretary, IACC

Oni Celestin, Ph.D.*
Health Science Policy Analyst

Katrina Ferrara, Ph.D.*
Health Science Policy Analyst

Steven Isaacson, L.M.S.W.
Autism Policy Analyst

Tianlu Ma, Ph.D.*
Health Science Policy Analyst

Rebecca Martin, M.P.H.*
Public Health Analyst

Angelice Mitrakas, B.A.*
Management Analyst

Luis Valdez-Lopez, M.P.H.
Health Science Policy Analyst

Jeffrey Wiegand, B.S.*
Web Development and
Digital Outreach Manager

* Also a staff member of the Office of Autism Research Coordination (OARC),
within the Office of National Autism Coordination (ONAC)