

INTERAGENCY AUTISM COORDINATING COMMITTEE (IACC)

2017-2018 AUTISM SPECTRUM DISORDER RESEARCH
PORTFOLIO ANALYSIS REPORT



OFFICE OF
AUTISM RESEARCH
COORDINATION
NATIONAL INSTITUTES OF HEALTH

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PORTFOLIO ANALYSIS REPORT

Prepared by the Office of Autism Research Coordination (OARC),
on behalf of the Interagency Autism Coordinating Committee (IACC)



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Note

The *2017-2018 IACC Autism Spectrum Disorder Research Portfolio Analysis Report* was originally released in April of 2021. It was revised in December of 2021 to include updated project data that were not available at the time of the initial release.

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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 ASD research and services, as well as public stakeholders, including self-advocates, family members of children and adults with ASD, advocates, service providers, and researchers, who represent a variety of perspectives from within the autism community. The IACC membership is composed to ensure that the Committee is equipped to address the wide range of issues and challenges faced by individuals and families affected by autism.

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

Through these and other activities, the IACC provides guidance and recommendations to HHS and partners with other federal departments and agencies, research and advocacy organizations, and the broader autism community to accelerate research and enhance services with the goal of profoundly improving the lives of people with ASD and their families.

For more information about the IACC, see <http://www.iacc.hhs.gov>.

Please note: 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 terms "autism" and "autism spectrum disorder (ASD)" are used interchangeably throughout this document unless otherwise noted.

INTRODUCTION AND ANALYSIS FRAMEWORK

The Office of Autism Research Coordination (OARC) is the office within the National Institutes of Health (NIH) that manages the activities of the Interagency Autism Coordinating Committee (IACC). In 2008, OARC began issuing a series of *IACC Autism Spectrum Disorder (ASD) Research Portfolio Analysis Reports* to provide the IACC with comprehensive information about the status of autism research funding among federal agencies and private research organizations in the United States.

In 2009, the IACC produced its first *Strategic Plan for Autism Spectrum Disorder Research*, providing a framework to guide the efforts of federal and private funders of autism research and developed with extensive input from a broad array of federal and public stakeholders. The **2016-2017 IACC Strategic Plan for Autism Spectrum Disorder** organizes research priorities around seven general topic areas represented as community-focused “Questions.” Each Question includes three to four primary Objectives; there is also one Cross-Cutting Objective on the topic of ASD in females. For the most recent 2018-2019 Strategic Plan Update, the Committee agreed that the 2016-2017 IACC Strategic Plan reflected a comprehensive review of the state of the field and therefore no updates to the Objectives were needed. For more details on the Objectives and a description of the latest advances in the field represented by each Question, please reference the 2016-2017 Strategic Plan and the **2018-2019 Strategic Plan Update**.

The *IACC Portfolio Analysis Reports* align data on individual research-related projects with Objectives in the *IACC Strategic Plan*, providing an accounting of how much funding has supported projects related to *Strategic Plan* Objectives and highlighting trends. This information has been used to help the IACC in their efforts to monitor ASD research and track funding progress made each year on the Objectives in the *IACC Strategic Plan*. The **2016 Portfolio Analysis Report** was the first portfolio analysis measuring progress made toward the 23 Objectives in the 2016-2017 IACC Strategic Plan. The present 2017-2018 IACC ASD Research Portfolio Analysis Report continues to monitor research funding progress on the 2016-2017 IACC Strategic Plan Objectives, as well as provide an analysis of progress that was made from 2008-2018. In addition, the 2017-2018 Portfolio Analysis Report includes an analysis of projects focused on racial and ethnic disparities in ASD research and introduces a Question 6 subcategory analysis that provides more detail on the breadth of research on ASD lifespan-related issues. These new sections of the portfolio analysis will be described in greater detail within the report.

In order to ensure that the portfolio analysis represents the most current and comprehensive view possible of the autism research landscape in the U.S., OARC and the IACC periodically review available information about autism research funded by U.S. organizations and add new funders willing to partner with the IACC in this effort. In 2017 and 2018, five new private funders were added to the portfolio analysis, each of which is supporting projects in their portfolios related to autism biomedical and services research.

To accompany the 2017-2018 IACC ASD Research Portfolio Analysis Report, detailed federal and private organization project data are available in the Autism Research Database (ARD), accessible via the IACC website (<https://iacc.hhs.gov/funding/data/>). This database provides stakeholders with a centralized place from which to gather valuable information about ASD research that can support their efforts to serve the autism community.

The IACC Strategic Plan Questions and Corresponding Research Areas

The Office of Autism Research Coordination (OARC) requested information on 2017 and 2018 autism-related 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 for ASD*. 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 ASD, and why is early detection so important?

SCREENING & DIAGNOSIS

- 1 Strengthen the evidence base for the benefits of early detection of ASD.
- 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 ASD in order to facilitate timely linkage of individuals with ASD to early, targeted interventions and supports.

CROSS-CUTTING OBJECTIVE

- 1 Support research to understand the underlying biology of sex differences in ASD, 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.



QUESTION 2: What is the biology underlying ASD?

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 ASD.
- 2 Support research to understand the underlying biology of co-occurring conditions in ASD and to understand the relationship of these conditions to ASD.
- 3 Support large-scale longitudinal studies that can answer questions about the development of ASD from pregnancy through adulthood and the natural history of ASD across the lifespan.



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

RISK FACTORS

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



QUESTION 4: What treatments and interventions will help?

TREATMENTS & INTERVENTIONS

- 1 Develop and improve pharmacological and medical interventions to address both core symptoms and co-occurring conditions in ASD.
- 2 Create and improve psychosocial, developmental, and naturalistic interventions for the core symptoms and co-occurring conditions in ASD.
- 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

- 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 with ASD as they progress into and through adulthood?

LIFESPAN ISSUES

- 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 with ASD, 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 ASD community?

INFRASTRUCTURE & SURVEILLANCE

- 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 ASD surveillance systems to further understanding of the population of individuals with ASD, while allowing comparisons and linkages across systems as much as possible.

Figure 1. The seven Questions, corresponding research areas, and 23 Objectives of the 2016-2017 IACC Strategic Plan.

Subcategory Classification

In 2010, OARC introduced the subcategory classification system (**Figure 2**) to the *IACC Portfolio Analysis Report* to help the Committee and other readers of this report better understand the types of research encompassed by the projects in the research portfolio, especially those projects that are categorized as outside the specific Objectives of the *Strategic Plan* but within a Question’s research area. For the subcategory analysis, each project was assigned to a subcategory based on the research area it addressed. The application of subcategory coding to projects in the portfolio helps to divide the portfolio into easy-to-understand topical areas. Previously, projects in Question 6 (Lifespan Issues) were not assigned subcategories because the number of projects in this Question area was fairly small. This number has grown in recent years, however, and the *2017-2018 Portfolio Analysis Report* introduces five new subcategories for Question 6 (see below).



Figure 2. The subcategory classification system 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. The *2017-2018 Portfolio Analysis Report* introduces five new subcategories for Question 6 (Lifespan Issues). Appendix B provides detailed definitions of the subcategory research areas for each Question.

ASD RESEARCH FUNDERS AND FUNDING IN 2017 AND 2018

Who funded ASD research in 2017 and 2018?

Nine federal agencies and fourteen private funders provided their autism research funding information for the *2017-2018 ASD Research Portfolio Analysis Report*. These 23 agencies and organizations are listed in **Table 1**. The IACC and OARC routinely review the funding landscape and offer opportunities to new funders to join the IACC portfolio analysis effort in order to provide a more comprehensive depiction of federal and private contributions to ASD research in the U.S. For the present report, five new private organizations were identified and added to the analysis. These new additions are as follows: the Escher Fund for Autism/Escher Family Fund, the FRAXA Research Foundation, the Geisinger Autism & Developmental Medicine Institute, the New Jersey Governor’s Council for Medical Research and Treatment of Autism, and the Tuberous Sclerosis Alliance. Within the portfolios

of funders who focus on rare genetic disorders with strong links to autism, only projects that directly study aspects of autism were counted as autism projects and included in the present report analyses. The five new funders contributed 1.5% (\$5.6 million) and 0.44% (\$1.75 million) of total funding in 2017 and 2018, respectively. The research projects that are included by these new funders are important in understanding the ASD research landscape but do not dramatically change the portfolio’s trends. Some agencies and organizations included in previous years’ analyses did not have projects to report in 2017 or 2018 or chose not to participate in the present analysis. Brief summaries of the mission areas for each agency and organization that contributed to the *2017-2018 Portfolio Analysis* can be found in Appendix A of this report.

FEDERAL	PRIVATE
<ul style="list-style-type: none"> • Administration for Community Living (ACL) • Agency for Healthcare Research and Quality (AHRQ) • Centers for Disease Control and Prevention (CDC) • Department of Defense – Army (DoD-Army) • Department of Education (ED) • Environmental Protection Agency (EPA) • Health Resources and Services Administration (HRSA) • National Institutes of Health (NIH) • National Science Foundation (NSF) 	<ul style="list-style-type: none"> • Autism Research Institute (ARI) • Autism Science Foundation (ASF) • Autism Speaks (AS) • Brain & Behavior Research Foundation (BBRF) • Center for Autism and Related Disorders (CARD) • Escher Fund for Autism/Escher Family Fund (EFA) • FRAXA Research Foundation (FRAXA) • Geisinger Autism & Developmental Medicine Institute (GADMI) • New England Center for Children (NECC) • Organization for Autism Research (OAR) • Patient-Centered Outcomes Research Institute (PCORI) • Simons Foundation (SF) • The New Jersey Governor’s Council for Medical Research and Treatment of Autism (NJMRTA) • Tuberous Sclerosis Alliance (TSA)

Table 1. Projects from nine federal agencies and fourteen private organizations were included in the *2017-2018 IACC ASD Research Portfolio Analysis Report*.

How much ASD research was funded in 2017 and 2018?

Combined, the estimated federal and private investment in ASD research was \$381,876,434 in 2017 and \$394,212,761 in 2018. Overall funding for autism research increased by \$17.4 million from 2016 to 2017 and by \$12.3 million from 2017 to 2018. The addition of the five new private funders to the portfolio analysis accounted for 32% (\$5.6 million) of the increase from 2016 to 2017 and 14% (\$1.75 million) of the increase from 2017 to 2018. Without including the contributions of the five new funders, the funding increase from 2016 to 2017 was \$11.8 million, and the increase from 2017 to 2018 was \$10.6 million.

The relative proportions contributed by federal and private funders during this period remained relatively unchanged from year to year. In 2017, the federal government provided \$307.8 million in ASD research funding and accounted for 81% of overall funding. Private organizations provided \$74.1 million in funding, which accounted for 19% of the total funding in 2017 (**Figure 3**). In 2018, the federal government provided \$326.9 million in ASD research funding and accounted for 83% of overall funding. Private organizations provided \$67.4 million, which accounted for 17% of the total funding in 2018 (**Figure 4**).

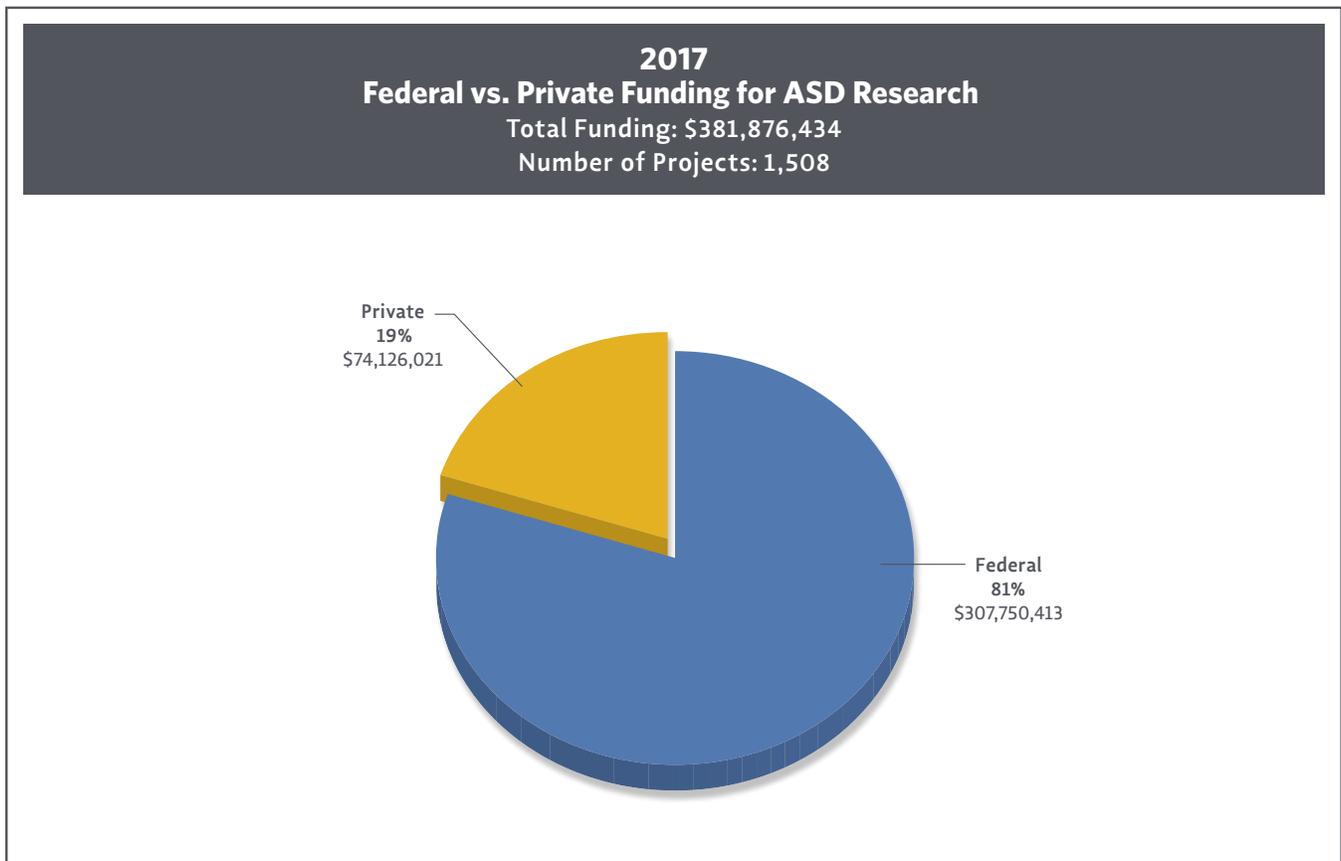


Figure 3. In 2017, 81% of ASD research was provided by federal sources, while 19% of funding was provided by private organizations.

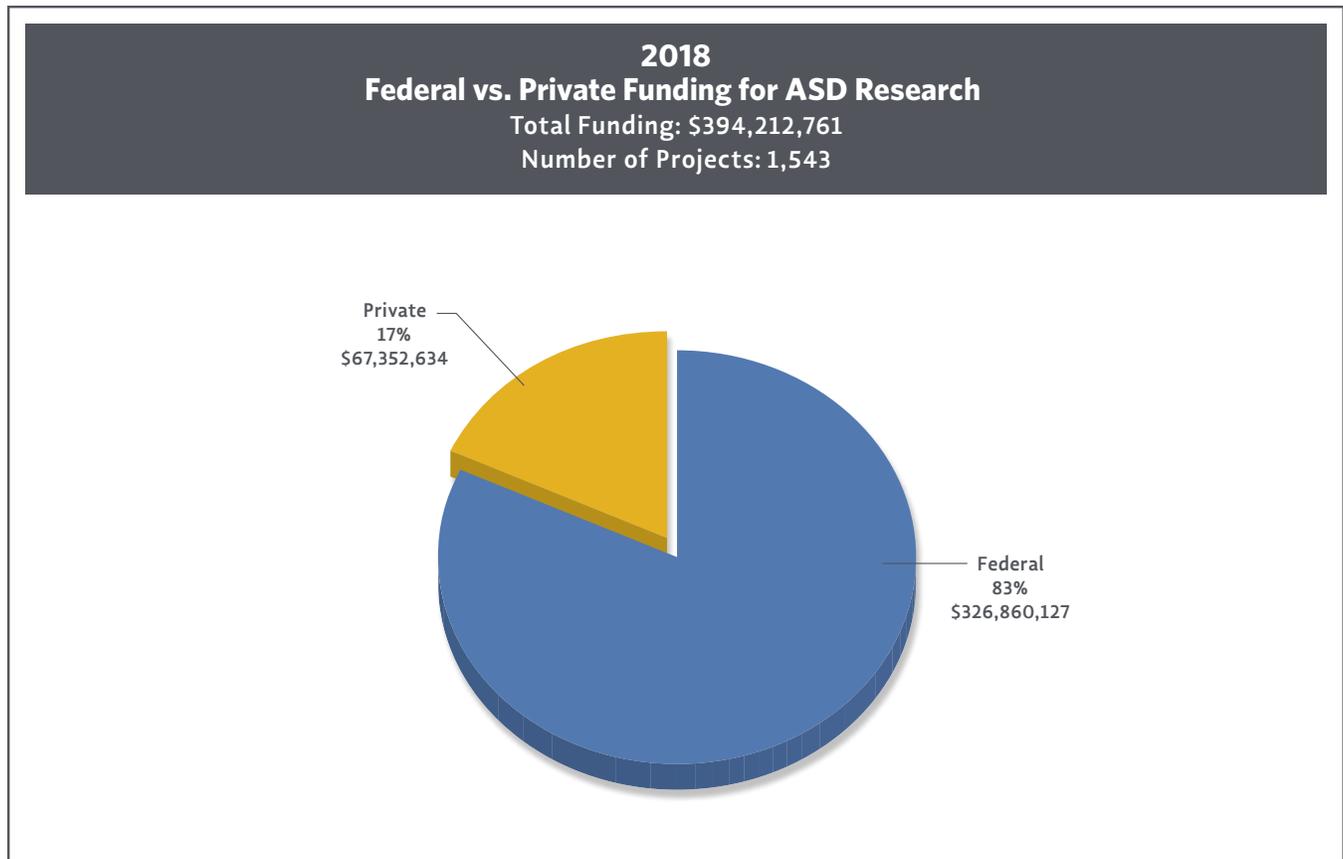


Figure 4. In 2018, 83% of ASD research was provided by federal sources, while 17% of funding was provided by private organizations.

What funding trends were observed?

- ASD research funding increased from 2016 to 2018. In 2016, combined federal and private investment in ASD research was \$364.4 million. In 2017, the combined federal and private funding was \$381.9 million, an increase of 4.8% from the previous year. In 2018, the combined federal and private funding was \$394.2 million, an increase of 3.2% from 2017 (**Figure 5**). The addition of five new private funders to the *Portfolio Analysis Report* accounted for a portion of these yearly increases but not all (see previous section for details).
- The amount of federal investment in ASD research increased 5.5% in 2017 (\$307.8 million) from 2016 (\$291.7 million). It increased 6.2% in 2018 (\$326.9 million) from 2017.
- The amount of private investment in ASD research increased 2% in 2017 (\$74.1 million) from 2016 (\$72.7 million). It decreased 9.1% in 2018 (67.4 million) from 2017.
- As stated in previous *IACC Portfolio Analysis Reports*, the American Recovery and Reinvestment Act (ARRA), which provided an additional \$63.9 million in 2009 and \$59.9 million in 2010 to support autism research projects, created a temporary increase in total autism research funding levels during those years, resulting in a high of \$408.6 million in reported funding in 2010. In 2011, levels significantly decreased in comparison to 2010 but have been slowly increasing in recent years.

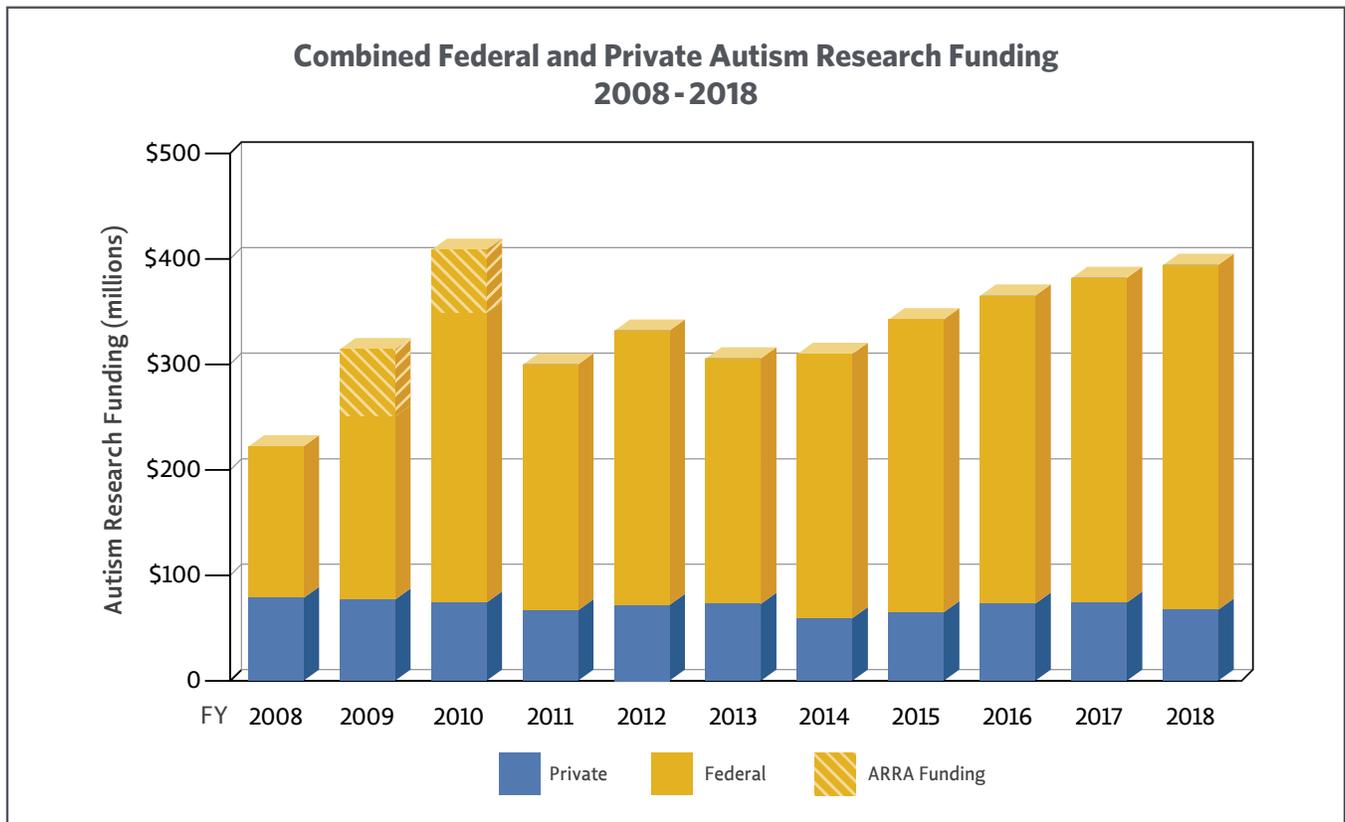


Figure 5. This figure illustrates levels of autism research funding from combined federal and private sources during 2008-2018 based on data collected for the *IACC Portfolio Analysis* of those years.

Where is research being funded in the U.S.?

Figure 6 shows the distribution of autism research projects across the U.S. funded by both federal agencies and private organizations in 2018. The map shows that research is concentrated along the east and west coasts of the U.S. 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 2017 are Yale University and the University of California, Davis. In 2018, in addition to Yale University, the University of California, San Francisco was a top funded institution. The University of California, Davis has many investigators collaborating on major 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 new **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**. The University of California, San Francisco includes researchers also involved in the SSC and the **Autism Sequencing Consortium (ASC)**, two major research initiatives investigating the genetic composition of ASD.

Many of the other institutions with significant amounts of funding are involved in large genetic, biological, and environmental research networks in an effort 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 had the largest number of projects in 2017 and 2018.

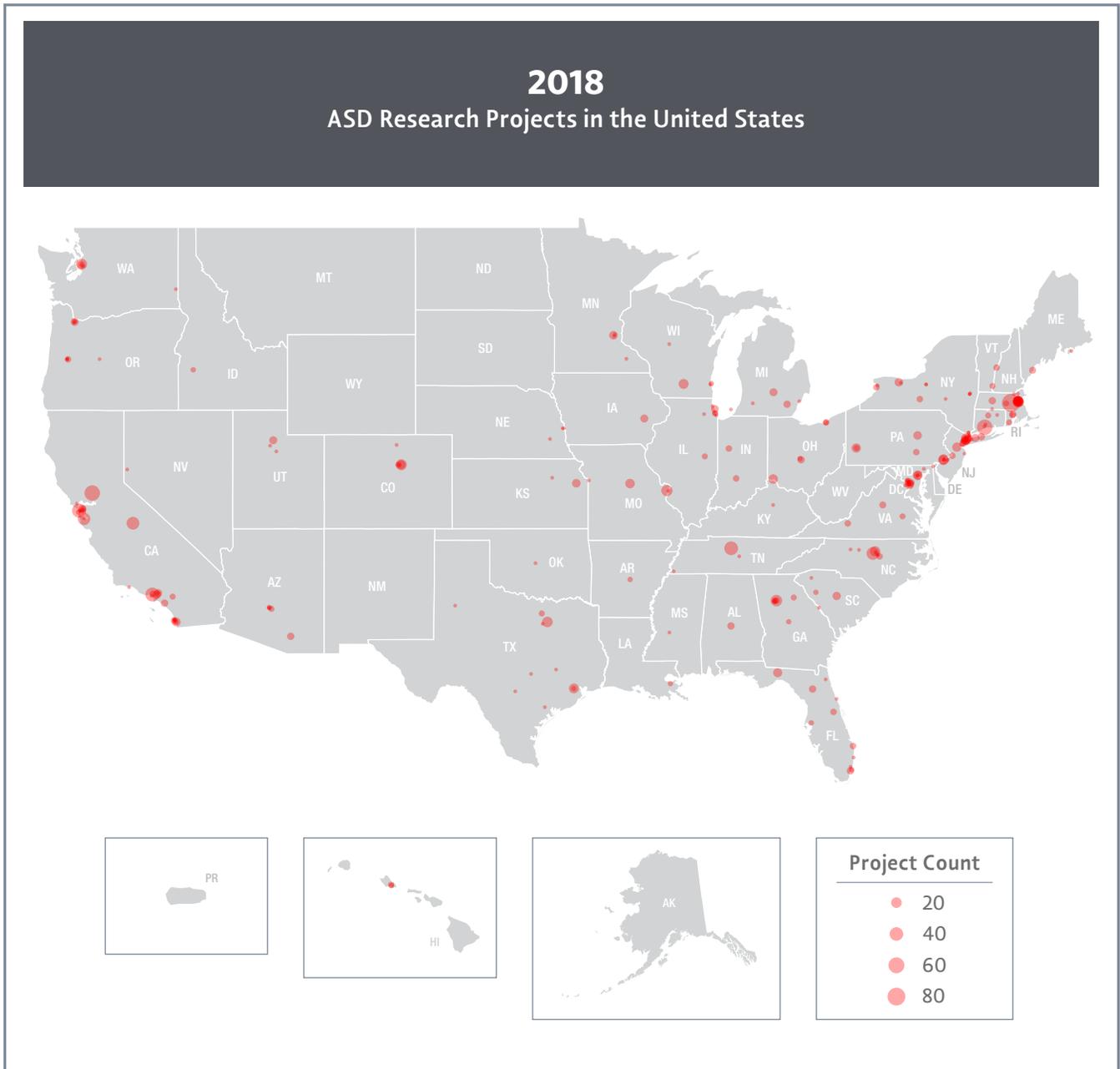


Figure 6. A map of the United States displaying the geographic distribution of autism-related research projects in 2018 funded by federal agencies and private organizations.

<i>Which U.S. institutions had the highest levels of funding in 2017 and 2018?</i>					
2017			2018		
Institution	Funding Amount	Project Count	Institution	Funding Amount	Project Count
Yale University	\$23,213,557	53	University of California, San Francisco	\$23,532,985	84
University of California, Davis	\$20,790,859	61	Yale University	\$22,653,002	61
University of California, Los Angeles	\$12,949,918	42	University of California, Davis	\$18,774,068	55
University of California, San Diego	\$12,282,101	35	University of California, San Diego	\$14,183,592	34
University of North Carolina, Chapel Hill	\$10,193,081	33	University of California, Los Angeles	\$12,665,795	42
National Institutes of Health - Intramural	\$9,263,100	12	National Institutes of Health - Intramural	\$9,886,842	9
University of Rochester	\$8,801,038	11	Stanford University	\$9,726,935	31
Stanford University	\$8,614,935	31	Drexel University	\$8,086,635	20
Drexel University	\$7,329,527	20	Washington University, St. Louis	\$7,435,650	23
Vanderbilt University	\$7,233,063	45	Massachusetts General Hospital	\$7,350,538	20

Table 2. Institutions with the most ASD-related research funding from federal and private sources in 2017 and 2018.

<i>Which states had the highest levels of funding in 2017 and 2018?</i>					
2017			2018		
State	Funding Amount	Project Count	State	Funding Amount	Project Count
California	\$80,062,765	291	California	\$83,499,573	282
New York	\$43,512,924	142	Massachusetts	\$39,111,089	231
Massachusetts	\$38,357,051	229	New York	\$38,503,289	145
Maryland	\$29,190,996	58	Maryland	\$28,936,874	45
Connecticut	\$23,291,057	57	Connecticut	\$24,098,417	67
Pennsylvania	\$21,617,332	87	Pennsylvania	\$22,113,779	89
North Carolina	\$16,998,820	64	North Carolina	\$16,740,739	61
Georgia	\$10,417,396	44	Florida	\$10,354,383	39
Florida	\$9,052,043	33	Georgia	\$9,916,057	42
Tennessee	\$7,776,659	47	Washington	\$9,177,308	33

Table 3. States with the most ASD-related research funding from federal and private sources in 2017 and 2018.

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

While the majority of U.S. ASD research funding is awarded to investigators at U.S. institutions, several of the agencies and organizations from which the IACC/OARC collects information invest in ASD research internationally. While a few federal agencies funded projects at international institutions, most of the international research was supported by private organizations (**Table 4**). In 2017, 20 countries outside the U.S. received support for ASD research from U.S. agencies and organizations represented in the portfolio analysis, with total funding of international projects amounting to \$9.3 million and 72 projects (**Table 5**). Overall in 2017, 2.4% of total funding went towards institutions outside of the U.S., and 4.8% of all projects were at international institutions. The countries that

received the largest portion of international funding in 2017 were the United Kingdom and Canada.

In 2018, 17 countries outside the U.S. received support for ASD research from agencies and organizations represented in the *Portfolio Analysis*, with total funding of international projects amounting to \$11.8 million and 75 projects (**Table 5**). Overall in 2018, 3% of total funding went towards institutions outside of the U.S., and 4.9% of all projects were at international institutions. As in previous years, most of this international research was supported by private organizations. As in 2017, the countries that received the largest portion of international funding in 2018 were Canada and the United Kingdom.

<i>U.S. Funders Supporting International ASD Research in 2017 and 2018</i>	
New England Center for Children	Brain & Behavior Research Foundation
Simons Foundation	Autism Speaks
FRAXA Research Foundation	National Institutes of Health
Escher Fund for Autism/Escher Family Fund	Autism Science Foundation
Autism Research Institute	

Table 4. List of U.S. funders of international ASD research in 2017 and 2018.

COUNTRIES RECEIVING U.S. FUNDING FOR ASD RESEARCH IN 2017 & 2018

Country	2017 Funding Amount	2017 Project Count	2018 Funding Amount	2018 Project Count
Australia	\$216,833	5	\$199,649	5
Austria	\$99,559	1	\$99,789	1
Belgium	\$151,600	2	\$0	1
Canada	\$3,344,472	25	\$4,114,706	26
France	\$250,000	6	\$394,433	8
Germany	\$0	1	\$0	0
Hong Kong	\$120,000	1	\$240,000	1
Ireland	\$290,750	3	\$217,700	3
Israel	\$91,997	2	\$0	3
Italy	\$150,504	2	\$208,068	5
Netherlands	\$17,500	2	\$88,796	4
Portugal	\$5,000	2	\$0	0
Pakistan	\$0	1	\$0	0
Singapore	\$67,500	1	\$0	1
Spain	\$16,079	1	\$16,079	1
Sweden	\$0	0	\$35,000	1
Switzerland	\$34,892	1	\$149,525	2
Taiwan	\$0	1	\$0	0
Turkey	\$0	1	\$0	1
United Arab Emirates	\$2,100	1	\$2,200	1
United Kingdom	\$4,362,001	13	\$6,026,179	11
Total	\$9,265,786	72	\$11,792,123	75

Table 5. Countries outside of the U.S. that received funding from U.S. federal agencies or private organizations to support ASD research in 2017 and 2018.

How much ASD research funding did each funder provide in 2017?

In 2017, the 23 agencies and organizations that participated in the portfolio analysis supported 1,508 ASD research projects, totaling \$381,876,434 (**Table 6**). The National Institutes of Health (NIH) was the leading federal (and overall) funder of ASD research in 2017 with a total of \$249.6 million, funding 551 projects. NIH funding for autism research increased by \$15.2 million from 2016 to 2017. The next largest federal funder was the Department of Education (ED), with \$17.4 million, followed by the Centers for Disease

Control and Prevention (CDC), with \$15.3 million. ED's research funding decreased slightly from 2016, by \$2.2 million. The CDC's funding stayed relatively constant from 2016 to 2017. As in previous years, the Simons Foundation (SF) and Autism Speaks (AS) were the largest private funders of ASD research in 2017, with investments of \$55.3 million and \$9 million, respectively. The percentage of overall ASD research funding provided by each agency and organization in 2017 is depicted in **Figure 7**.

2017 ASD RESEARCH FUNDING BY AGENCY/ORGANIZATION

Funding Agency/Organization	2017 Funding	Project Count
National Institutes of Health (NIH)	\$249,564,078	551*
Simons Foundation (SF)	\$55,319,669	308
Department of Education (ED)	\$17,380,036	84
Centers for Disease Control and Prevention (CDC)	\$15,337,228	28
Department of Defense - Army (DoD-Army)	\$13,648,386	41
Autism Speaks (AS)	\$8,997,408	84
Health Resources and Services Administration (HRSA)	\$7,714,518**	52
The NJ Governor's Council for Medical Research and Treatment of Autism (NJMRTA)	\$2,798,035	7
FRAXA Research Foundation (FRAXA)	\$2,303,714	23
National Science Foundation (NSF)	\$1,926,563	39
Brain & Behavior Research Foundation (BBRF)	\$1,693,792	80
Administration for Community Living (ACL)	\$1,122,986	3
Autism Science Foundation (ASF)	\$905,373	50
Center for Autism and Related Disorders (CARD)	\$765,000	10
Environmental Protection Agency (EPA)	\$764,214	1
New England Center for Children (NECC)	\$301,540	86
Agency for Healthcare Research and Quality (AHRQ)	\$292,404	4
Tuberous Sclerosis Alliance (TSA)	\$231,818	4
Geisinger Autism & Developmental Medicine Institute (GADMI)	\$222,858	4
Autism Research Institute (ARI)	\$220,517	17
Organization for Autism Research (OAR)	\$189,301	19
Patient-Centered Outcomes Research Institute (PCORI)	\$124,997	9
Escher Fund for Autism/Escher Family Fund (EFA)	\$52,000	4
Grand Total	\$381,876,434	1,508

*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. The table lists the total funding and number of projects provided by the 23 federal agencies and private organizations included in the portfolio analysis for 2017. Together, the agencies and organizations funded 1,508 projects, representing an overall investment of \$382 million.

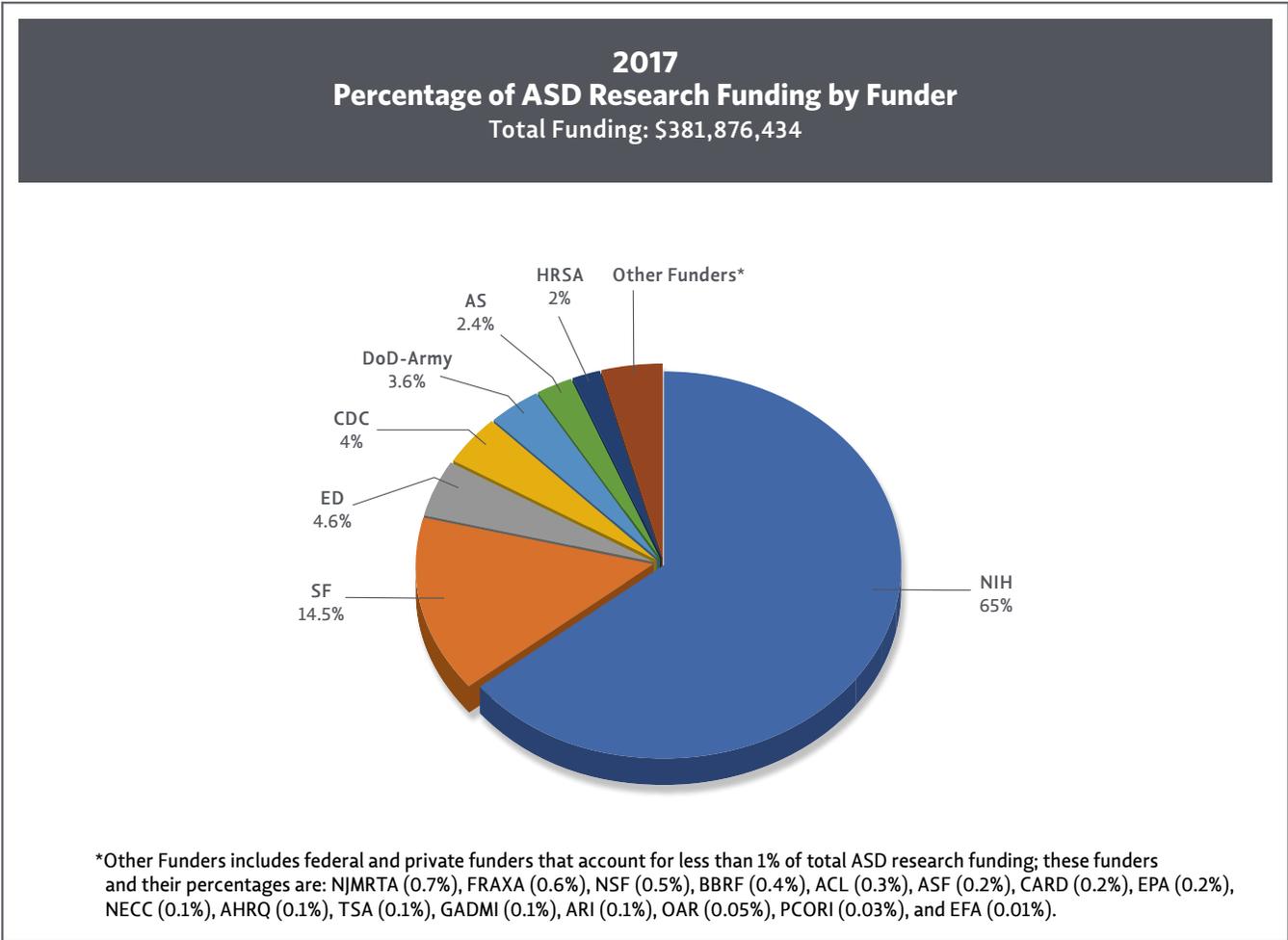


Figure 7. Percentage of total ASD research funding contributed by the 23 federal agencies and private organizations included in the 2017 portfolio. NIH provided the largest proportion of funding (65%), while Simons Foundation provided the largest private investment (14.5%).

How much ASD research funding did each funder provide in 2018?

In 2018, the agencies and organizations that participated in the portfolio analysis supported 1,543 ASD research projects totaling \$394,212,761 (**Table 7**). The National Institutes of Health (NIH) continued to lead federal and overall ASD research funding, with a total of \$273.7 million, funding 621 projects. NIH funding for autism research increased by \$24.1 million from 2017 to 2018. The next largest federal funder was the Department of Education (ED), with \$18.6 million, followed by the Centers for Disease Control and Prevention (CDC), with \$14.4 million. ED's

research funding increased by \$1.2 million from 2017, while the CDC's funding stayed relatively the same. As in previous years, the Simons Foundation (SF) and Autism Speaks (AS) were the largest private funders of ASD research in 2018, with investments of \$57.6 million and \$5.7 million, respectively. SF increased ASD research funding by \$2.3 million from 2017, and AS saw a decrease of \$3 million. The percentage of overall ASD research funding provided by each agency and organization in 2018 is depicted in **Figure 8**.

2018 ASD RESEARCH FUNDING BY AGENCY/ORGANIZATION

Funding Agency/Organization	2018 Funding	Project Count
National Institutes of Health (NIH)	\$273,664,260	621
Simons Foundation (SF)	\$57,638,035	344
Department of Education (ED)	\$18,613,583	93
Centers for Disease Control and Prevention (CDC)	\$14,375,460	28
Health Resources and Services Administration (HRSA)	\$7,561,591	50
Department of Defense - Army (DoD-Army)	\$6,677,362	45
Autism Speaks (AS)	\$5,696,282	52
National Science Foundation (NSF)	\$2,916,180	39
Administration for Community Living (ACL)	\$2,344,950	9
Brain & Behavior Research Foundation (BBRF)	\$811,911	65
The NJ Governor's Council for Medical Research and Treatment of Autism (NJMRTA)	\$800,000	8
Agency for Healthcare Research and Quality (AHRQ)	\$706,741	3
FRAXA Research Foundation (FRAXA)	\$665,043	22
Autism Science Foundation (ASF)	\$643,396	34
Patient-Centered Outcomes Research Institute (PCORI)	\$227,721	10
New England Center for Children (NECC)	\$223,525	81
Autism Research Institute (ARI)	\$193,157	10
Organization for Autism Research (OAR)	\$167,965	13
Escher Fund for Autism/Escher Family Fund (EFA)	\$103,500	9
Tuberous Sclerosis Alliance (TSA)	\$100,568	3
Geisinger Autism & Developmental Medicine Institute (GADMI)	\$81,532	3
Environmental Protection Agency (EPA)	\$0	1
Grand Total	\$394,212,761	1,543

Table 7. The table lists the total funding and number of projects provided by the federal agencies and private organizations included in the portfolio analysis for 2018. Together, the agencies and organizations funded 1,543 projects, representing an overall investment of \$394.2 million.

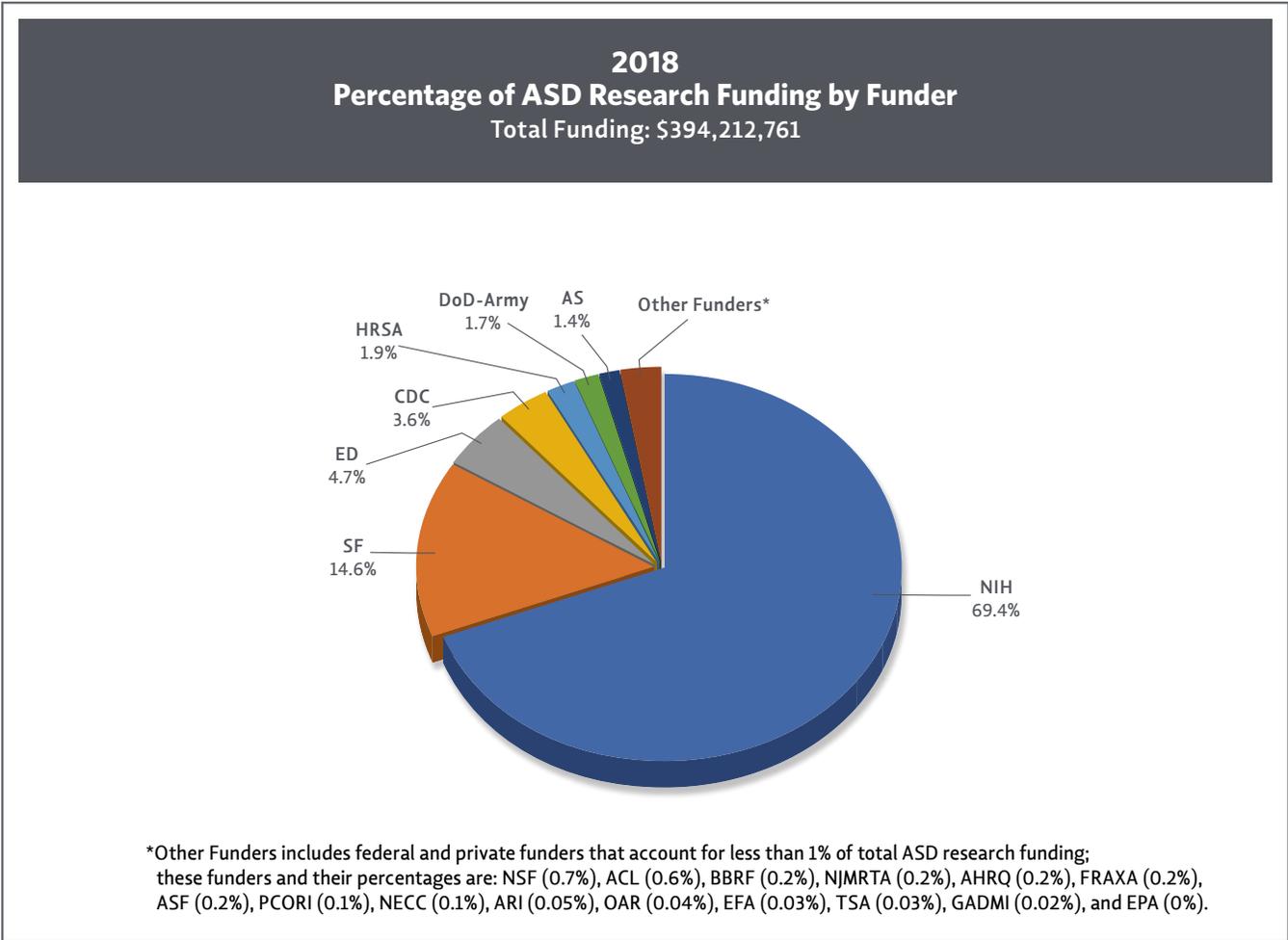


Figure 8. The figure illustrates the percentage of total ASD research funding contributed by the federal agencies and private organizations included in the 2018 portfolio. NIH provided the largest proportion of funding (69.4%), while Simons Foundation provided the largest private investment (14.6%).

Summary of ASD Research Funding in 2017 and 2018

The 2016-2017 IACC Strategic Plan calls for a doubling of the 2015 ASD research budget to \$685 million by 2020. To accomplish this goal, the IACC recommended a nearly 15% annual increase in ASD research funding across combined federal and private funders. The committee recognized that this was an ambitious goal, but it believed that such an increase could 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 \$394.2 million in 2018, representing a 8.2% increase in funding. While this did not meet the 2016-2017 IACC Strategic Plan recommended 15% increase, ASD research did experience a substantial growth in funding during this period (Figure 9).

From 2008-2018, funding increased by 77.4%, demonstrating a continued overall growth in support of ASD research. However, ASD funding has undergone some fluctuations from one year to the next (Figure 5). An infusion of funds from the American Recovery and Reinvestment Act (ARRA) in 2009 and 2010 took autism research funding to its highest level to date, but funding levels decreased in 2011, with gradual increases over the next few years. In 2018, the ASD research portfolio was funded at the highest level since 2010, but this was still well below the level that would be required to meet the 2016-2017 IACC Strategic Plan budget recommendation. In future years, funding trends will continue to be monitored to determine progress toward meeting the IACC’s budget recommendation.

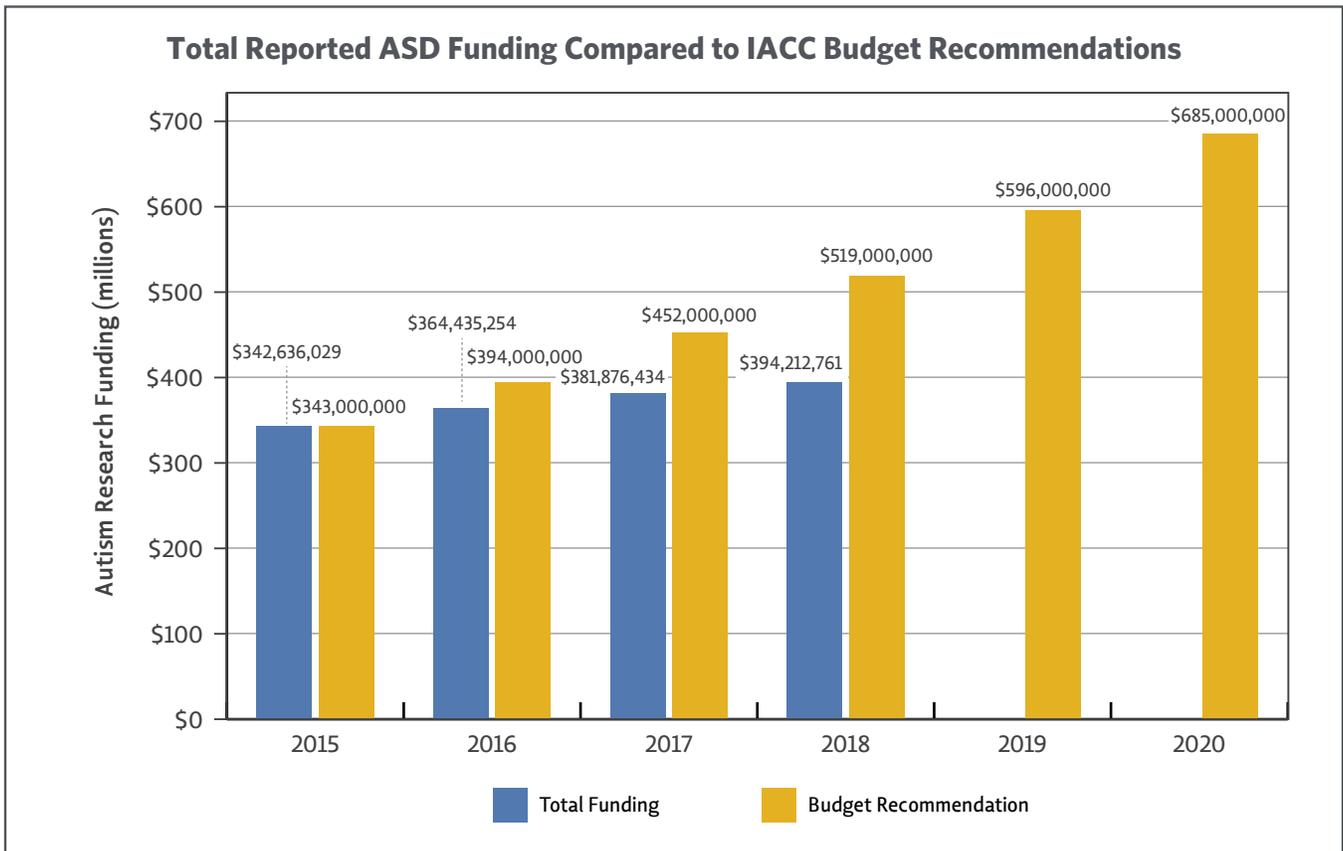


Figure 9. The IACC recommends a doubling of the combined federal and private ASD research budget to \$685 million by 2020. Based on 2017 and 2018 funding amounts, ASD research investment is increasing but is still not at the level of the IACC budget recommendation.

ASD RESEARCH AREAS AND FUNDING IN 2017-2018

What areas of ASD research were funded in 2017 and 2018?

To better understand what areas of research were funded in 2017 and 2018, projects were aligned with the Questions in the 2016-2017 IACC *Strategic Plan*. **Figures 10** and **11** illustrate the breakdown of the research funding per each of the *Strategic Plan's* seven Questions, which are related to Screening and Diagnosis (Q1), Biology (Q2), Risk Factors (Q3), Treatments and Interventions (Q4), Services (Q5), Lifespan Issues (Q6), and Infrastructure and Surveillance (Q7). Identifying how current research investments correspond to the *Strategic Plan* provides an understanding of how funders have directed investments across each of the 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.

ASD research funding in 2017 and 2018 supported projects relevant to all seven Questions in the *IACC Strategic Plan for ASD Research*. As in previous years, the largest portion of funding addressed the underlying Biology of ASD (Question 2). This was followed by Question 3 (Risk Factors), research aimed at identifying potential causes and risk factors for ASD. Research into Treatments and Interventions for ASD (Question 4), including behavioral therapies, pharmacological

treatments, and technology-based interventions, followed. Investment in research Infrastructure and Surveillance (Question 7) received nearly a tenth of funding in both years. Research focused on improving tools for Screening and Diagnosis (Question 1) as well as Services (Question 5) followed in funding levels. Lifespan Issues (Question 6) remained the smallest area of funding each year. In 2017, the percentages of total funding were as follows: Question 1, 7%; Question 2, 39%; Question 3, 21%; Question 4, 15%; Question 5, 6%; Question 6, 2%; Question 7, 9% (**Figure 10**). In 2018, the percentages of total funding were as follows: Question 1, 6%; Question 2, 44%; Question 3, 19%; Question 4, 13%; Question 5, 6%; Question 6, 3%; Question 7, 9% (**Figure 11**). Overall, from 2017 to 2018, funding increased for projects focused on Biology (Question 2), Lifespan Issues (Question 6), and Infrastructure and Surveillance (Question 7). Funding for research on Services (Question 5) remained relatively flat, and funding was slightly reduced across the remaining research areas. Subsequent sections in this report provide analyses of changes in funding over time (2008-2018) for each Question area.

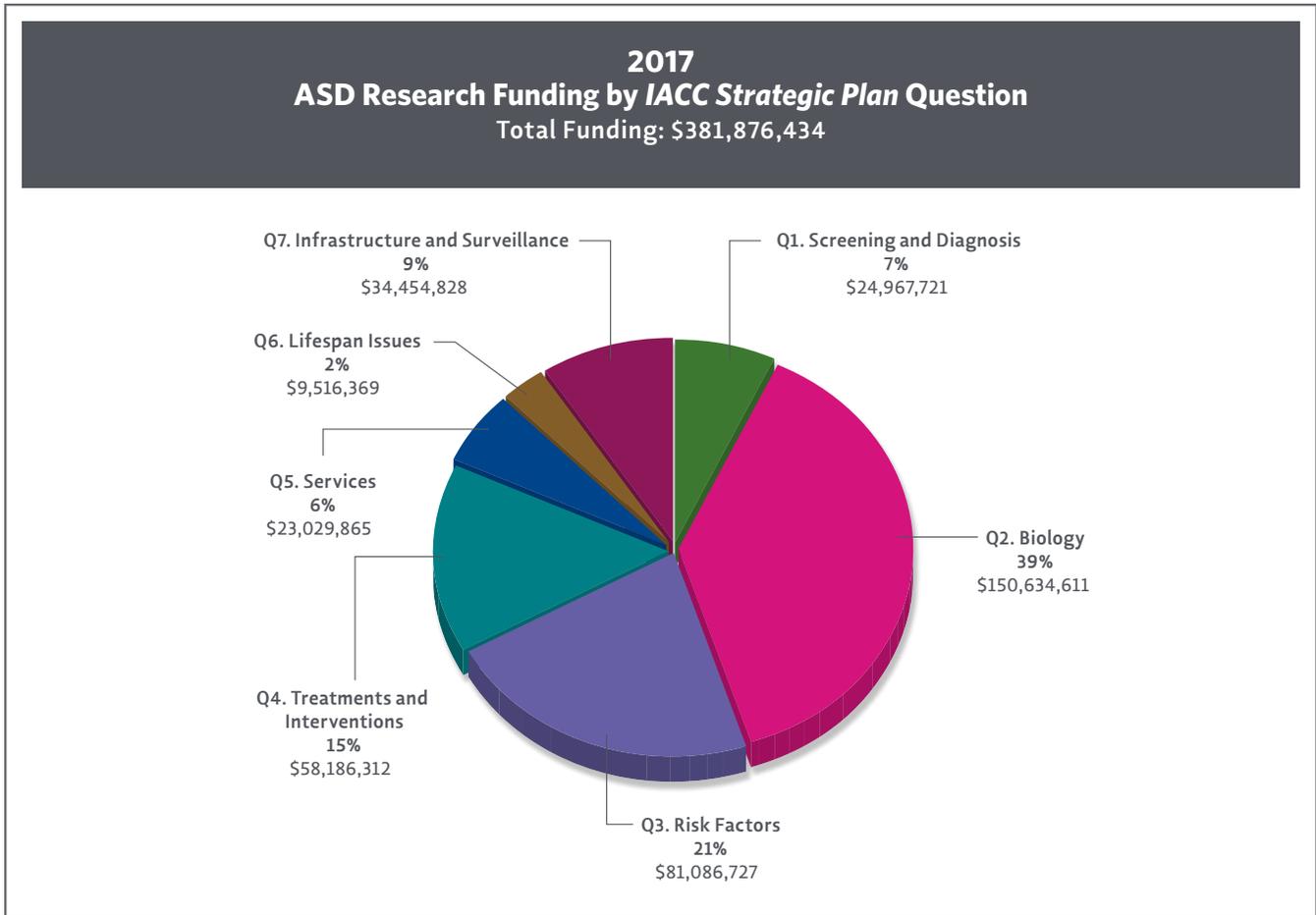


Figure 10. 2017 ASD research funding by IACC Strategic Plan Question. Topic areas are defined by each Question in the IACC Strategic Plan. The seven Questions of the Strategic Plan are represented in the clockwise direction, beginning with Screening and Diagnosis (Question 1) and ending with Infrastructure and Surveillance (Question 7).

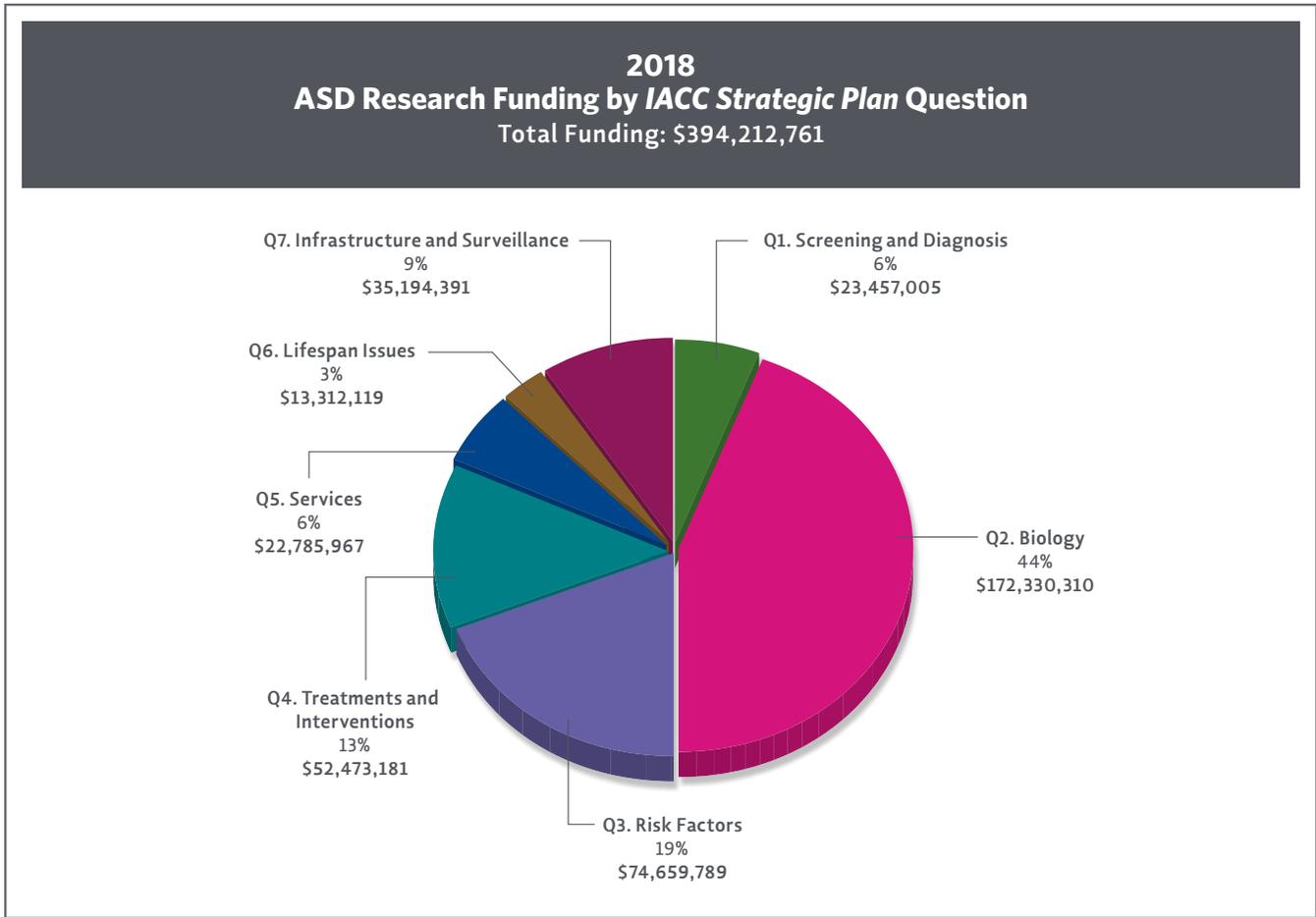


Figure 11. 2018 ASD research funding by IACC Strategic Plan Question.

When the number of projects that align with each Question is considered, as opposed to the total funding for these projects, the distribution is slightly different due to differences in the relative sizes of projects falling under each of the seven Question topics. In 2017, the percentages of total projects were as follows: Question 1, 6%; Question 2, 38%; Question 3, 17%;

Question 4, 18%; Question 5, 8%; Question 6, 4%; Question 7, 9% (**Figure 12**). In 2018, the percentages of total projects were as follows: Question 1, 6%; Question 2, 39%; Question 3, 16%; Question 4, 17%; Question 5, 7%; Question 6, 5%; Question 7, 9% (**Figure 13**). The proportion of projects remained relatively constant from one year to the next.

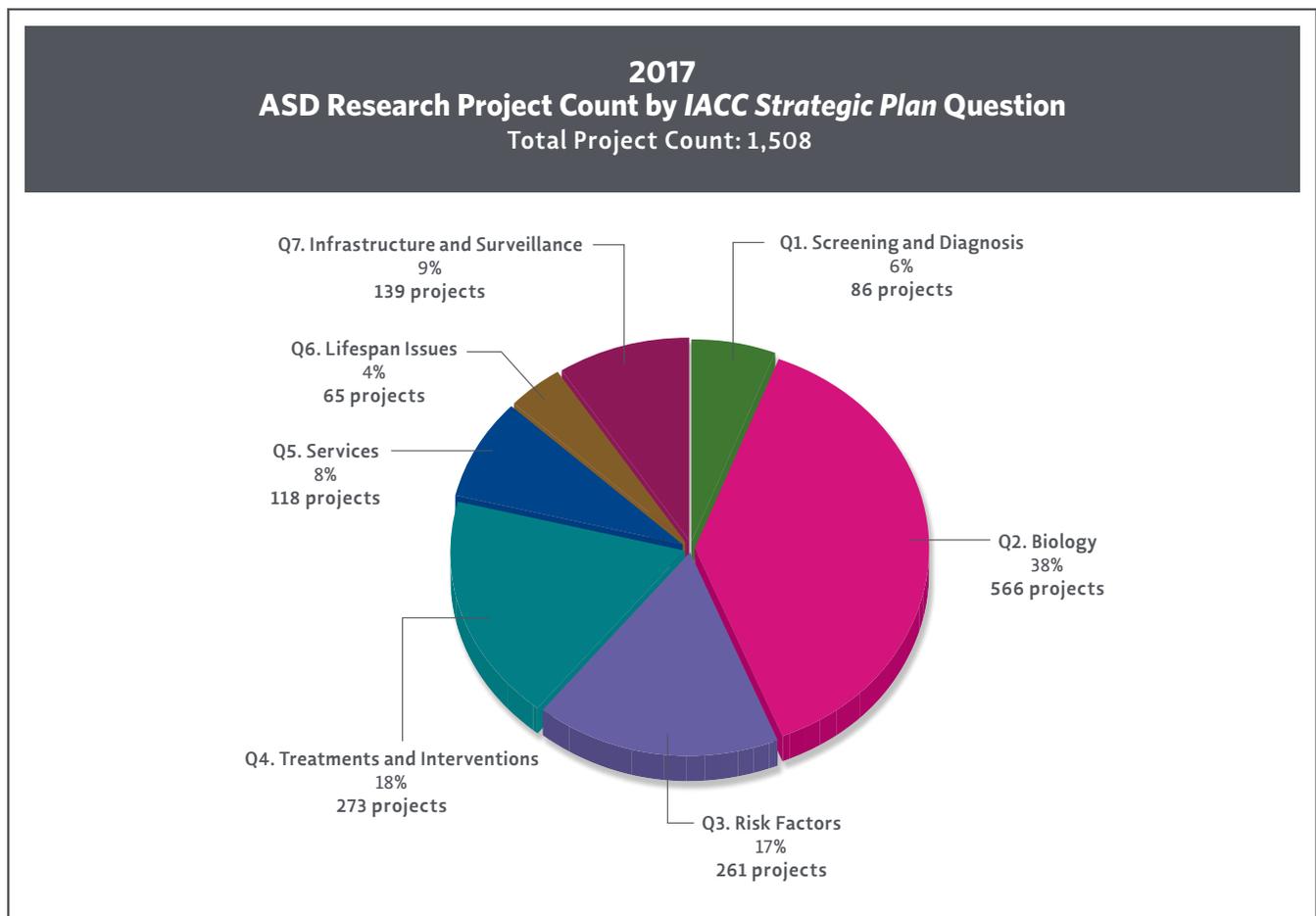


Figure 12. 2017 ASD research project counts by IACC Strategic Plan Question.

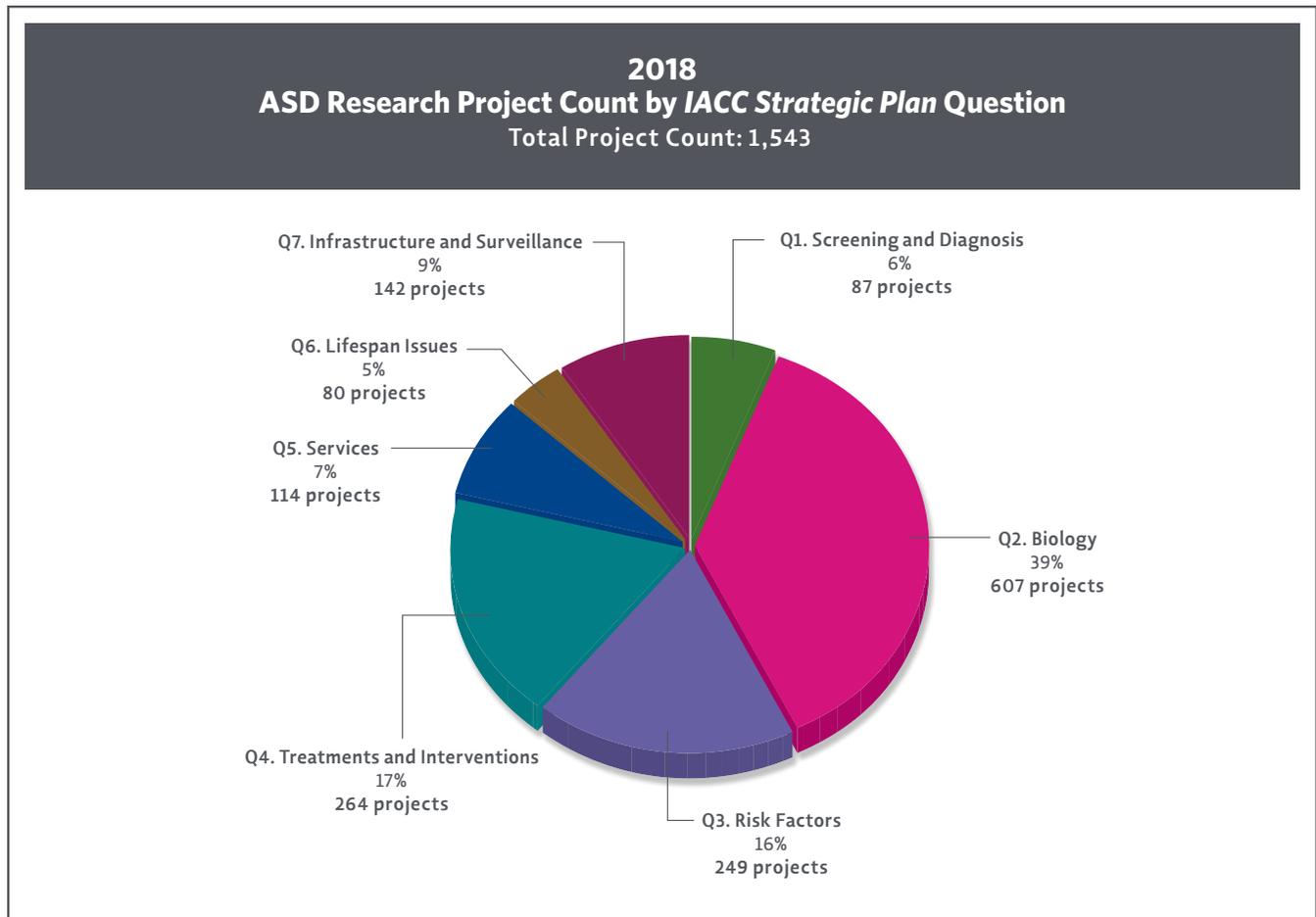


Figure 13. 2018 ASD research project counts by IACC Strategic Plan Question.

How many new research projects were added in 2017 and 2018 compared to ongoing research?

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. In 2017, 68% of overall ASD research funding went to ongoing projects while 32% went to new projects. In 2018, 77% of total ASD funding was assigned to ongoing projects while 23% were labeled new projects. Since most research projects are funded over multiple years, a larger number of ongoing projects compared to new projects is expected. In comparison to other Question areas, research related to Lifespan Issues (Question 6) had higher proportions of funding devoted to new

projects (74% in 2017 and 59% in 2018) (**Figure 14**). The IACC has emphasized the need to expand research in this area, which was highlighted in the *2016-2017 IACC Strategic Plan’s* budget recommendation. While Question 6 consistently has been the least funded research area over the years, a burst in newly-funded projects in this research area is promising for the field. In contrast, funding for Screening and Diagnosis (Question 1) and Risk Factors (Question 3) had the highest proportions of funding going to ongoing projects when compared to other Questions. The remaining research areas had similar proportions of funding devoted to ongoing projects.

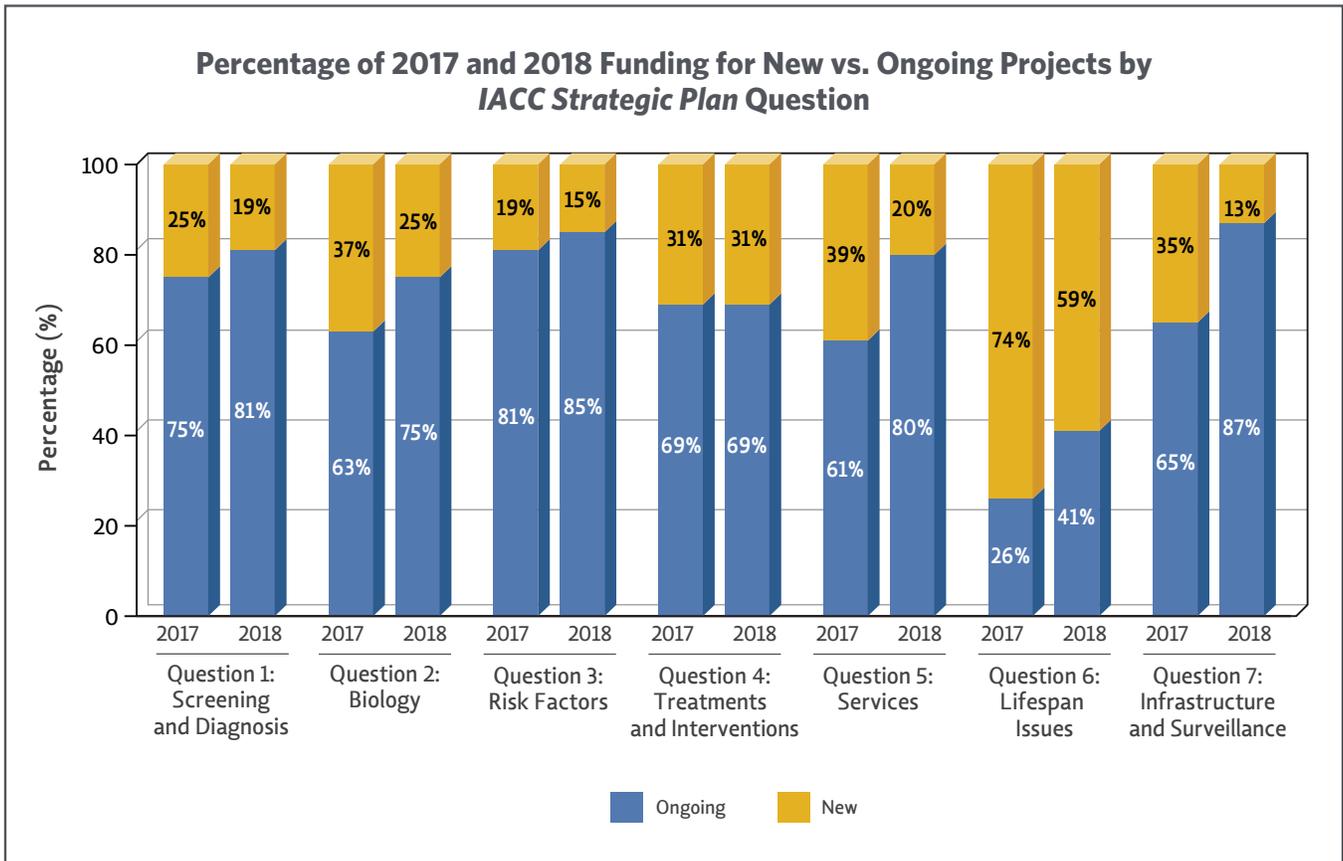


Figure 14. The percentages of 2017 and 2018 ASD research funding directed to ongoing versus new projects varies between *Strategic Plan* Questions.

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

The federal and private funders included in this *Portfolio Analysis Report* fund a wide range of autism-related research projects. As shown in **Figure 15**, federal and private funders contributed to funding for each of the Question areas in the *IACC Strategic Plan for ASD* in 2018. However, the proportions of federal and private funding vary by Question area, suggesting that some areas align more closely with federal or private mission areas, priorities, and/or capabilities. All Question areas

received more federal funding than private funding. The research areas that received the largest amount of private funding were projects investigating the Biology of ASD (Question 2), genetic and environmental Risk Factors of ASD (Question 3), and Infrastructure and Surveillance (Question 7). Although 2017 data is not presented, there were similar federal and private funding patterns for 2017 projects.

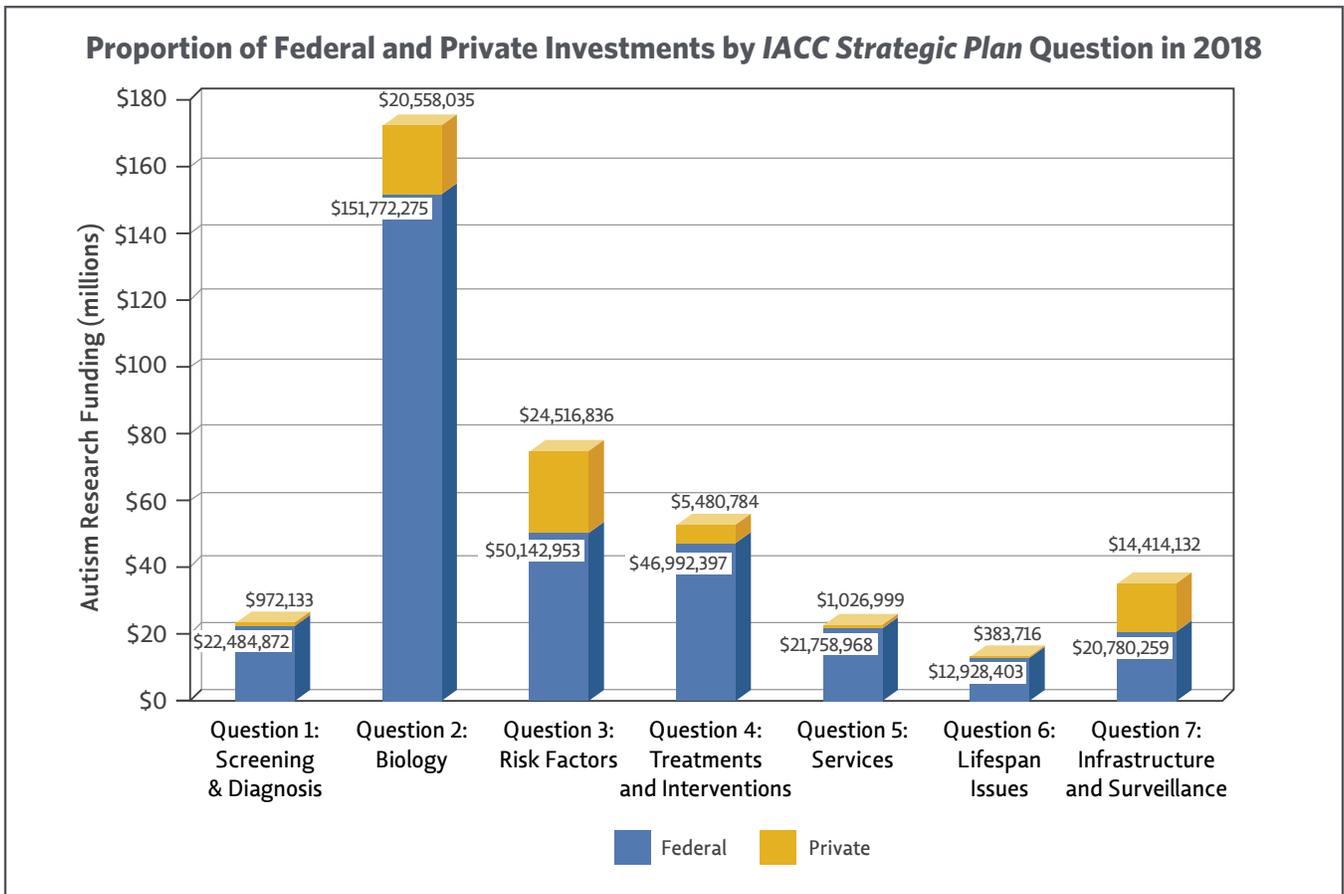


Figure 15. Federal and private funding was provided for each *Strategic Plan* Question area in 2018, although the proportion of federal versus private funding varied between Question areas.

Figure 16 shows the agencies and organizations that funded projects in 2018 in each of the seven Question areas of the *IACC Strategic Plan*. **Figure 17** illustrates the breadth of the mission areas of the funding agencies and organizations included in the *IACC Portfolio Analysis*

Report. These two figures demonstrate that while some agencies and organizations have broad portfolios that cover many different research areas described in the *IACC Strategic Plan*, others focus their efforts on a narrower range of research topics.

2018 Funder Contributions to Strategic Plan Questions

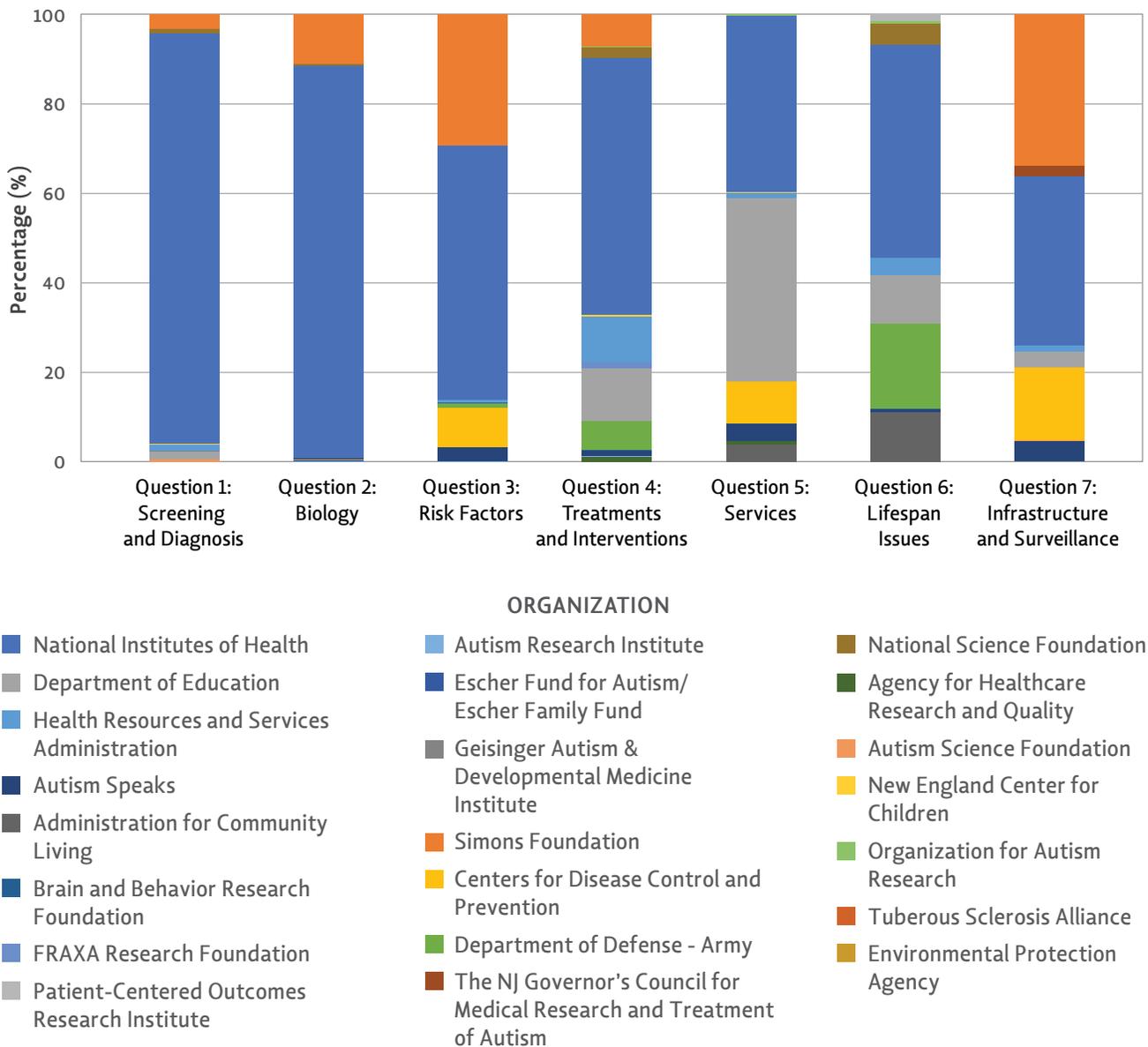


Figure 16. The proportion of each federal agency and private organizations' funding in the portfolio analysis organized by *IACC Strategic Plan* Question for 2018.

2018 Distribution of Funder Portfolios Across *Strategic Plan* Questions

- Question 1: Screening and Diagnosis
- Question 4: Treatments and Interventions
- Question 6: Lifespan
- Question 2: Biology
- Question 5: Services
- Question 7: Infrastructure and Surveillance
- Question 3: Risk Factors

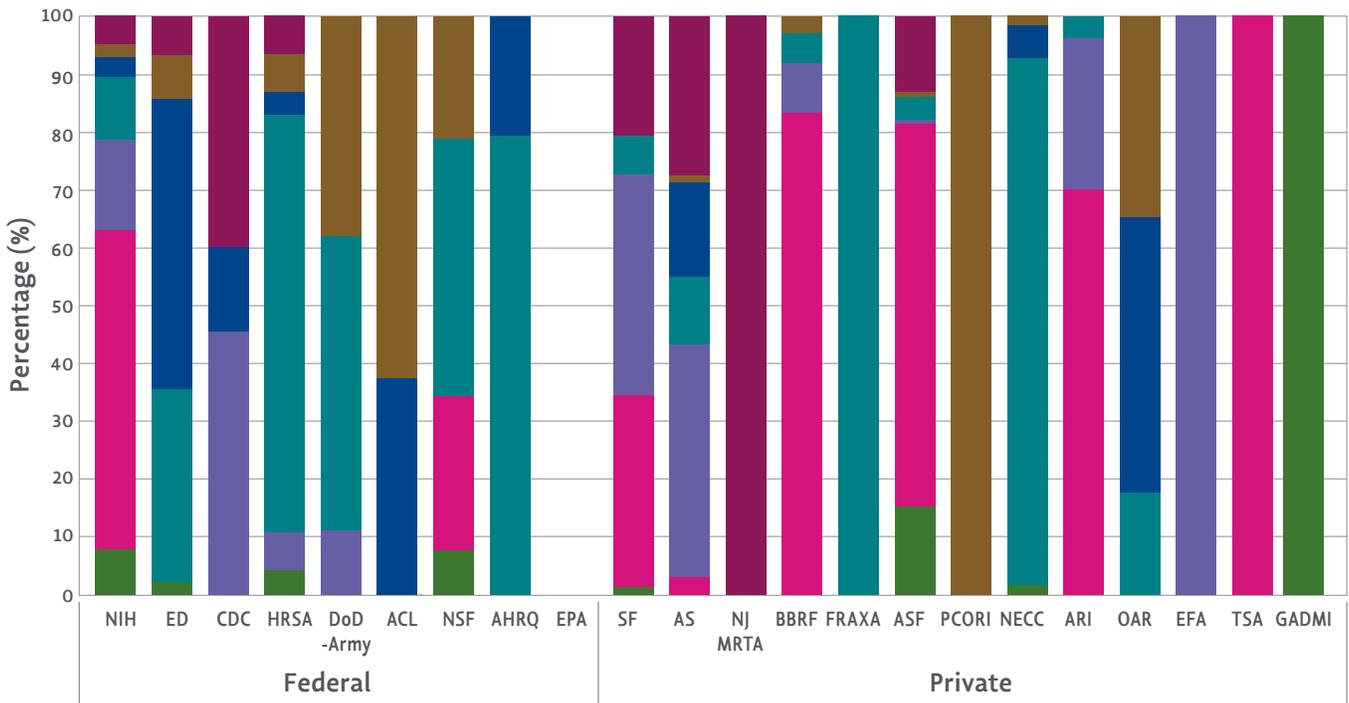


Figure 17. The portfolio of each federal agency and private organizations' ASD projects by *Strategic Plan* Question for 2018. Please note that this figure is based on funding amounts from 2018. Thus, while funders may support additional areas of research, this may not be reflected in this particular year.

How did the research projects funded in 2017 and 2018 align with the Objectives in the IACC Strategic Plan?

The 23 *IACC Strategic Plan* Objectives were developed by the IACC to recommend priorities for investment, and they represent areas where the Committee perceived gaps in research that required increased efforts. All autism research projects in 2017 and 2018 were matched with the best fitting Question and research Objective in the *IACC Strategic Plan*. In some cases, based on the project description, a given project did not fit closely with any of the *Strategic Plan* Objectives and could only be assigned to a *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 outlined in the *Strategic Plan*, or that represent 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 the progress of ASD research.

Analysis of the 2017 and 2018 project information determined the proportion of projects that fit within *Strategic Plan* Objectives versus the proportion that did not fit within *Strategic Plan* Objectives (**Figure 18**). In 2017, 3% of the funding went to projects that were designated as Core/Other. In 2018, 4% of the funding went to projects that were designated as Core/Other. These percentages follow closely with 2016’s proportion of projects categorized as Core/Other (4%). **Figure 19** illustrates the breakdown of funding within each *Strategic Plan* Question that was specific to the Objectives or designated as Core/Other.

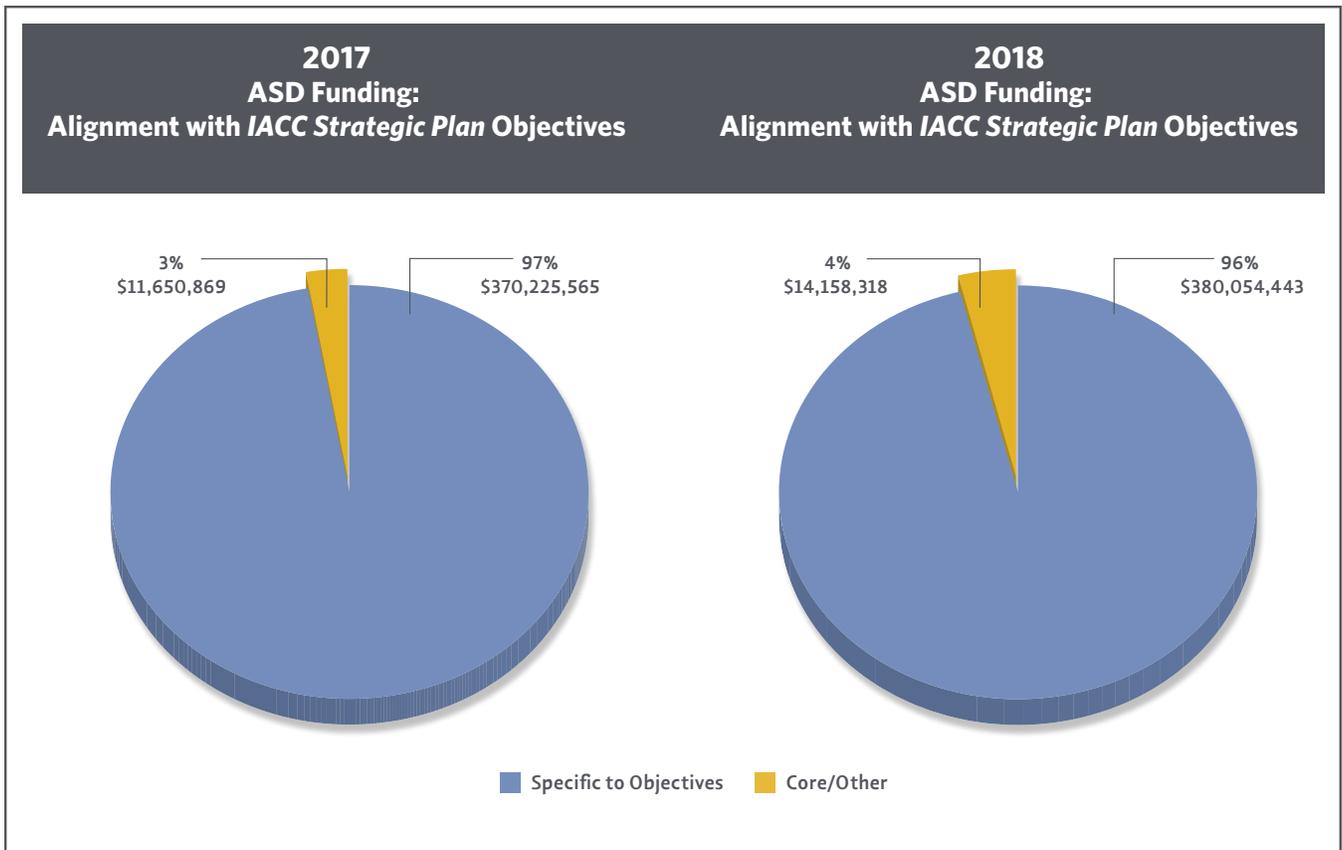


Figure 18. In 2017, 3% of funding went to projects that were not specific to a particular *IACC Strategic Plan Objective* and were designated as *Core/Other*. In 2018, 4% of projects were categorized as *Core/Other*.

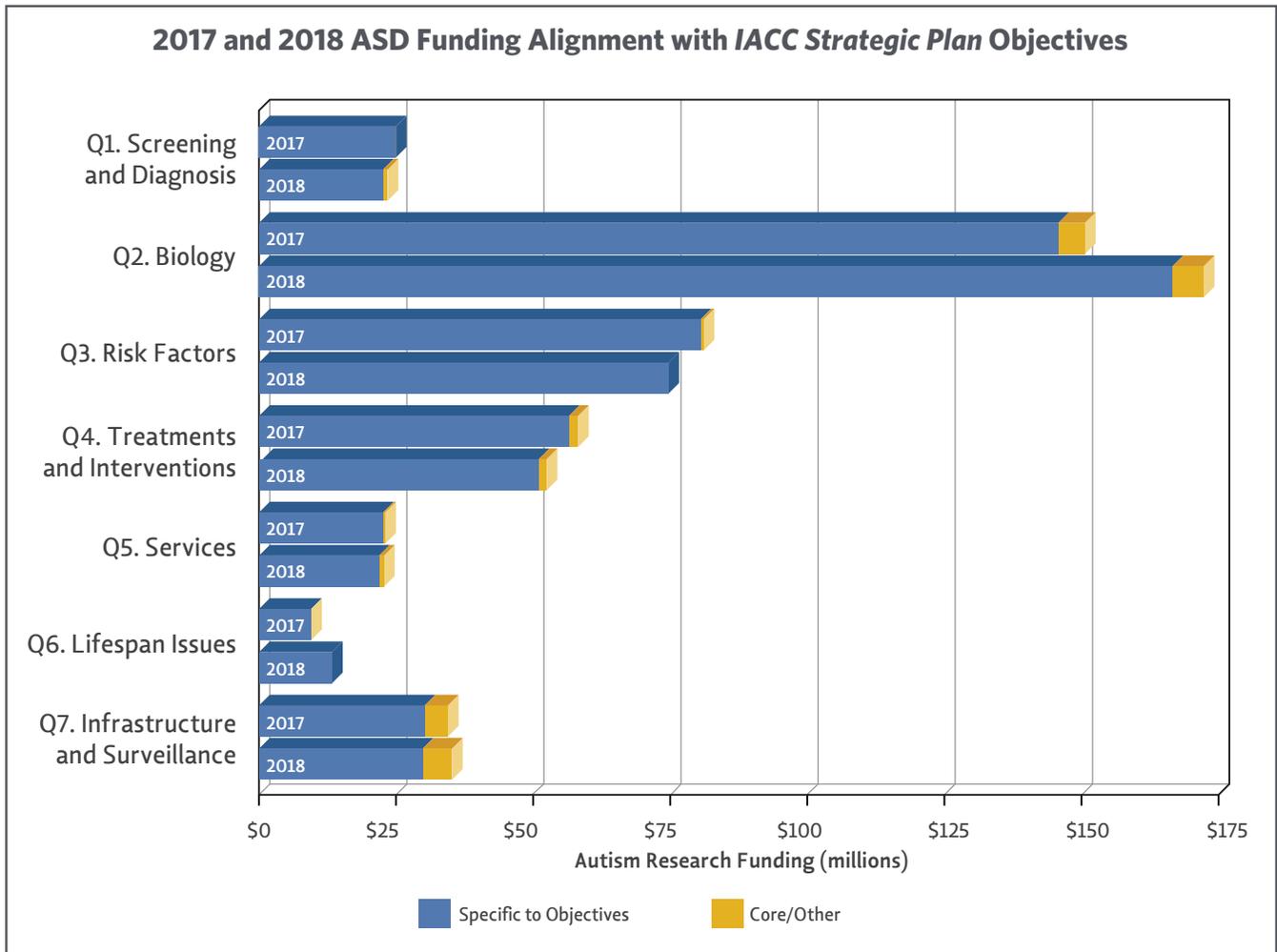


Figure 19. In 2017 and 2018, the majority of funding for ASD projects was assigned to a specific Objective within the *IACC Strategic Plan* Questions. However, each Question in the *Strategic Plan* contained projects that were not specific to a particular Objective, designated as Core/Other. Funding for projects that fall under specific Objectives are indicated in blue, and Core/Other projects are indicated in yellow. Subcategory analysis for each Question of the *Strategic Plan* provides a description of the research areas addressed by all projects, including those assigned to Core/Other.

Summary of Funding Toward *IACC Strategic Plan Objectives*

The 23 Objectives in the *Strategic Plan* describe specific research priorities identified by the IACC. Each ASD project that received funding in 2017 and/or 2018 was evaluated with respect to the 23 Objectives in the *2016-2017 IACC Strategic Plan for ASD* in order to determine which *Strategic Plan* Question and Objective it fulfilled. Analysis of the full portfolio of federally and privately funded projects yielded information about the funding progress that has been made towards the Objectives in the *2016-2017 IACC Strategic Plan*. Further discussion of the funding progress towards individual *Strategic Plan* Objectives is found in subsequent sections of this report. Future *Portfolio Analysis Reports* will monitor funding trends for each Objective.

The following sections in this report give an overview of the funding progress in 2017 and 2018 on research Objectives in each Question, analysis of subcategories for each Question, and a review of the overall trend in funding over time for each Question of the *Strategic Plan*.

ANALYSIS OF FUNDING TOWARD
IACC STRATEGIC PLAN OBJECTIVES
BY RESEARCH AREA

ANALYSIS OF 2017-2018 QUESTION 1 PORTFOLIO

When analyzing the distribution of research dollars across the seven Question areas described in the *IACC Strategic Plan*, projects assigned to Question 1 comprised 7% (\$25 million) of total ASD research funding in 2017 and 6% (\$23.5 million) of funding in 2018. A total of 86 projects were assigned to Question 1 in 2017, which was 6% of all projects. Similarly, 87 projects were aligned to Question 1 in 2018, also representing 6% of total projects. The largest funders of research pertaining to Question 1 in 2017 and 2018 were the National Institutes of Health, Simons Foundation, Department of Education, and the Health Resources and Services Administration. Funding progress made on Question 1 is measured through three primary Objectives and one Cross-Cutting Objective. **Figures 20** and **21** provide a detailed overview of each Objective's total funding in 2017 and 2018 as well as the number of projects assigned to each Objective.

In 2017 and 2018, all three Question 1 primary Objectives received funding. The Question 1 Objective receiving the most funding was 1.3, which aims to improve and develop new tools and service models for detecting ASD; it received 61% (\$15.3 million) of the Question 1 funding in 2017 and 54% (\$12.7 million) in 2018. **Objective 1.3** had most of the Question 1 projects; this corresponds to 64 projects in 2017 and 57 projects in 2018. This was followed by

Objective 1.2, which focuses on reducing disparities in early detection and access to services. In 2017, Objective 1.2 accounted for 23% (\$5.7 million) of Question 1 funding and included 14 projects. In 2018, Objective 1.2 approximated 24% of Question 1 funding (\$5.7 million) and included 15 projects. **Objective 1.1** received 16% (\$4 million) of Question 1 funding in 2017 and had seven projects; the goal of this Objective is to strengthen the evidence base for the benefits of early detection of ASD. In 2018, Objective 1.1 accounted for 18% (\$4.2 million) of Question 1 funding and included 11 projects. The **Cross-Cutting Objective (CC1)**, which focuses on understanding the sex differences in screening and diagnosing ASD under Question 1, did not have any projects in 2017 but had one project in 2018. This one project was focused on understanding the early symptomology differences between boys and girls. Only one project was categorized as Core/Other (i.e., projects not specific to Question 1 Objectives) in 2017; this project studied the integration of new technologies to assess visual and attentional influences on movement and imitative behavior in ASD. Three projects were considered Core/Other in 2018; these included continued funding for the one Core/Other project from 2017, a project investigating the etiologies of "complex" vs. "essential" autism, and a project focused on the neuroethics of predictive MRI testing of parental attitudes towards identification of ASD before the appearance of autistic characteristics.

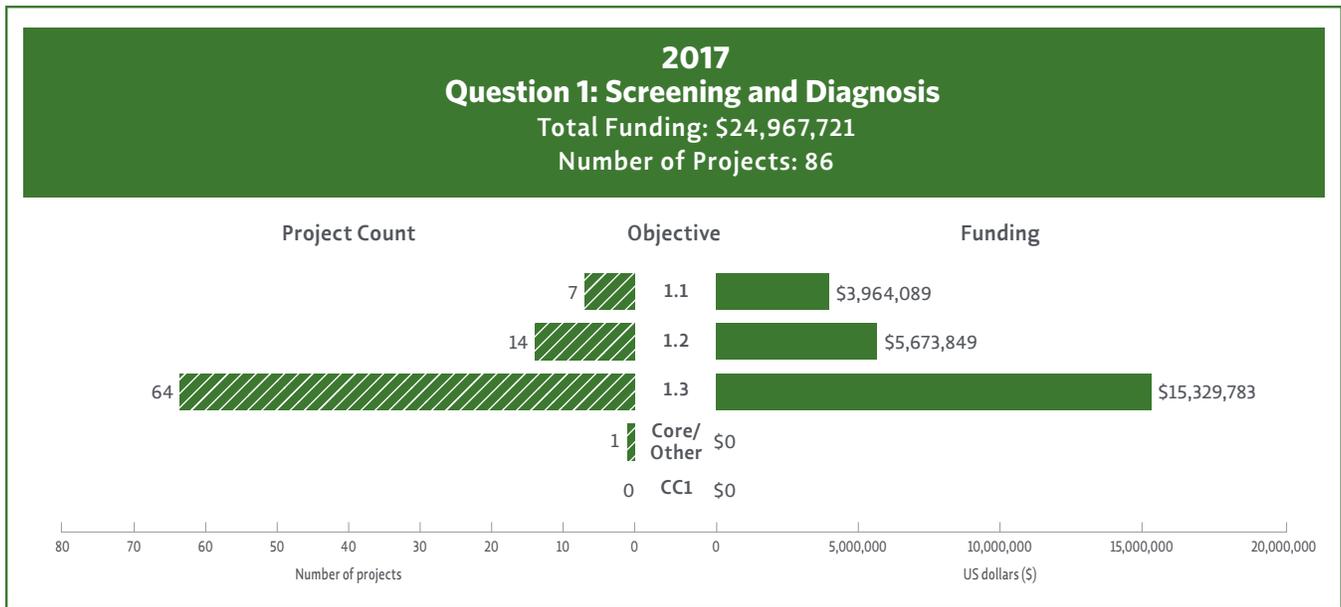


Figure 20. 2017 funding and project count by Question 1 Objectives. 1.1: Strengthen the evidence base for the benefits of early detection of ASD; 1.2: Reduce disparities in early detection and access to services; 1.3 Improve/validate existing or develop new tools, methods, and service delivery models for detecting ASD in order to facilitate timely linkage of individuals with ASD to early, targeted interventions and supports; Core/Other: Projects that do not align with Question 1 Objectives or support "core" activities in the autism research field; CC1: Support research to understand the underlying biology of sex differences in ASD, 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.

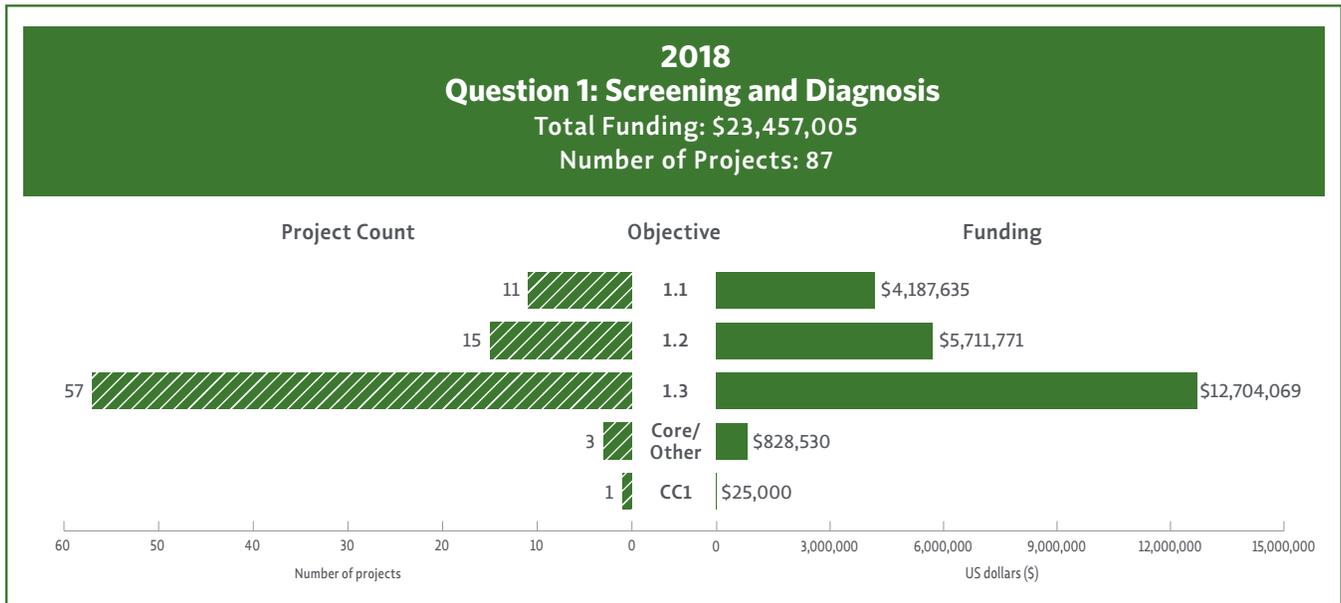


Figure 21. 2018 funding and project count by Question 1 Objectives. See Figure 20 caption above for descriptions of each Objective.

QUESTION 1 SUBCATEGORY ANALYSIS

Following the subcategory categorization scheme for the *IACC ASD Research Portfolio Analysis*, all 2017 and 2018 ASD projects were categorized into broad research-related topic areas or themes, including projects that did not fit within the specific research Objectives laid out in the *Strategic Plan*. This enables a comprehensive understanding of the distribution of all projects across the general research areas aligning with Question 1. Overall, projects in Question 1 were divided

into four subcategories: **Diagnostic and screening tools**; **Early signs and biomarkers**; **Intermediate phenotypes/Subgroups**; and **Symptomology** (Figures 22 and 23).

Of these four subcategories, the largest proportion of 2017 and 2018 funding was devoted to the development of **Diagnostic and screening tools** for ASD (59% in 2017; 64% in 2018); this included 42 projects in 2017

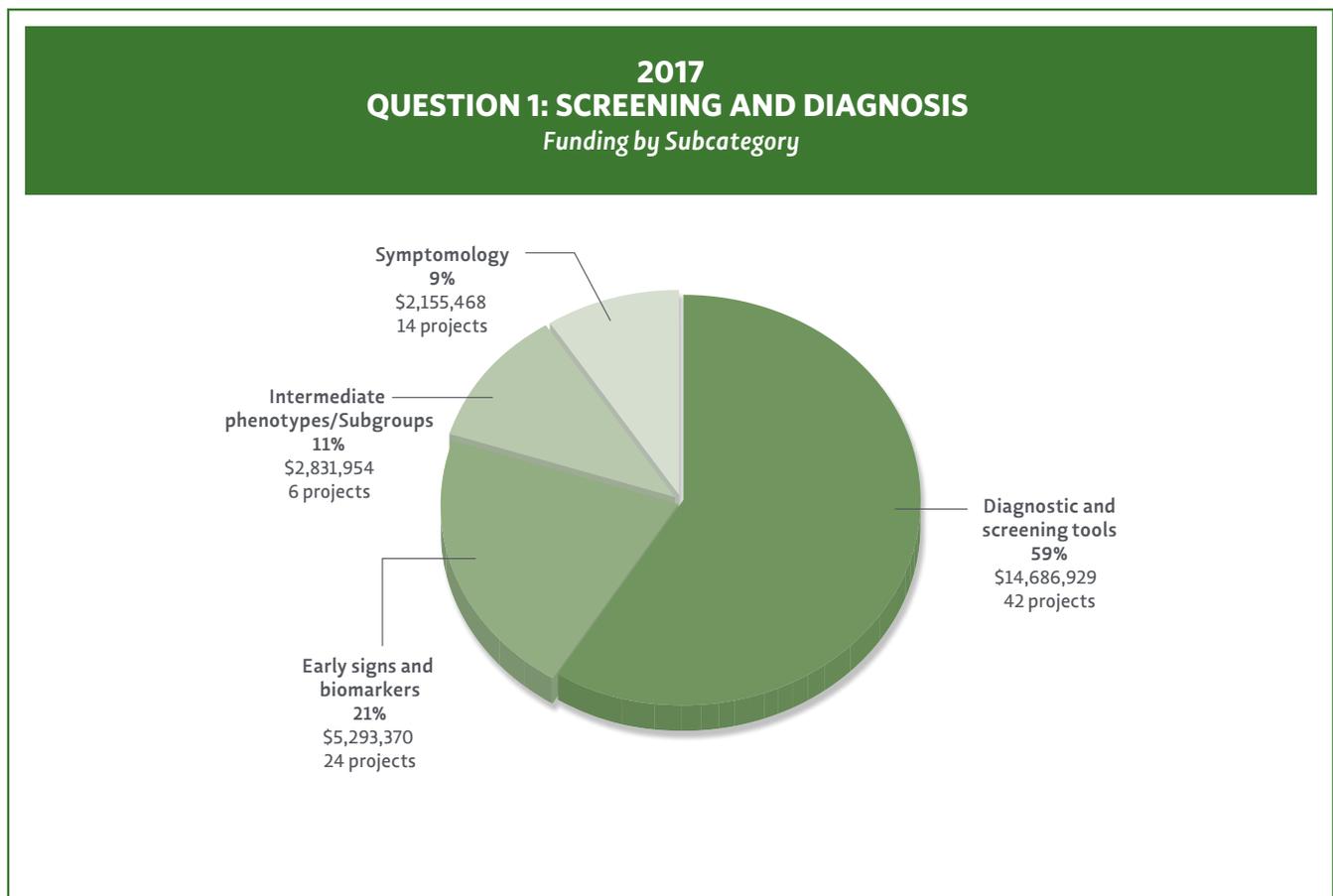


Figure 22. Question 1 funding by subcategory in 2017.

and 49 projects in 2018. Identifying **Early signs and biomarkers** was the second largest research investment in Question 1 (21%, 24 projects in 2017; 24%, 26 projects in 2018). 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 progress or treatment response. In 2017, identifying **Intermediate phenotypes/Subgroups** of

people with ASD received 11% of Question 1 funding and accounted for six projects. This was followed by research characterizing **Symptomology**, which was 9% of Question 1 funding and had 14 projects. In 2018, these last two subcategories both accounted for 6% of Question 1 funding; Intermediate phenotypes/Subgroups had five projects, and Symptomology included seven projects.

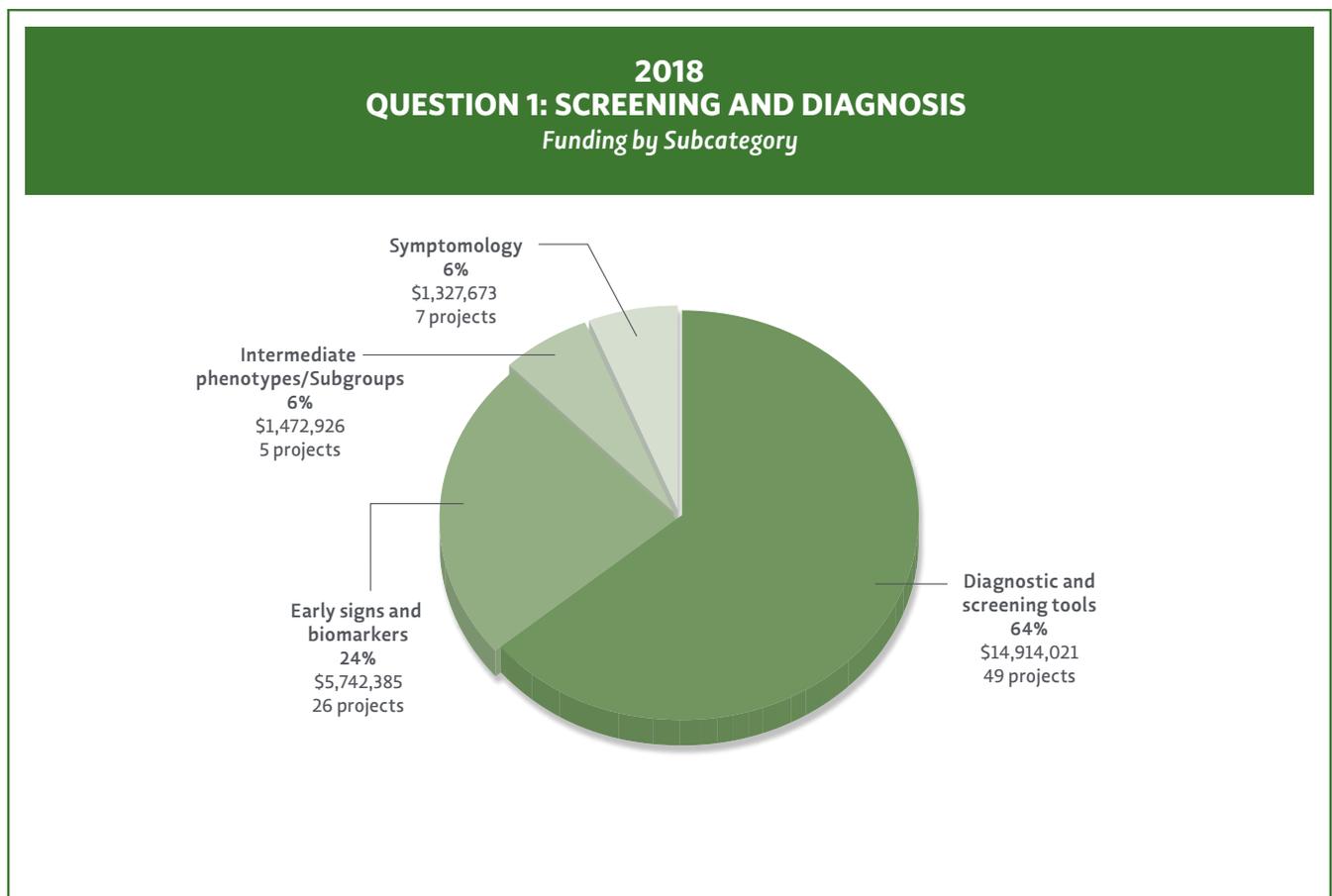


Figure 23. Question 1 funding by subcategory in 2018.

FUNDING PROGRESS MADE ON QUESTION 1 FROM 2008-2018

Figure 24 shows the trend in Question 1 funding over time. When considering annual funding for Question 1 from 2008-2018, portfolio analysis data showed that funding levels stayed relatively flat since 2008, with

the exception of 2009 and 2010, during which federal funding for autism research was increased due to the American Recovery and Reinvestment Act.

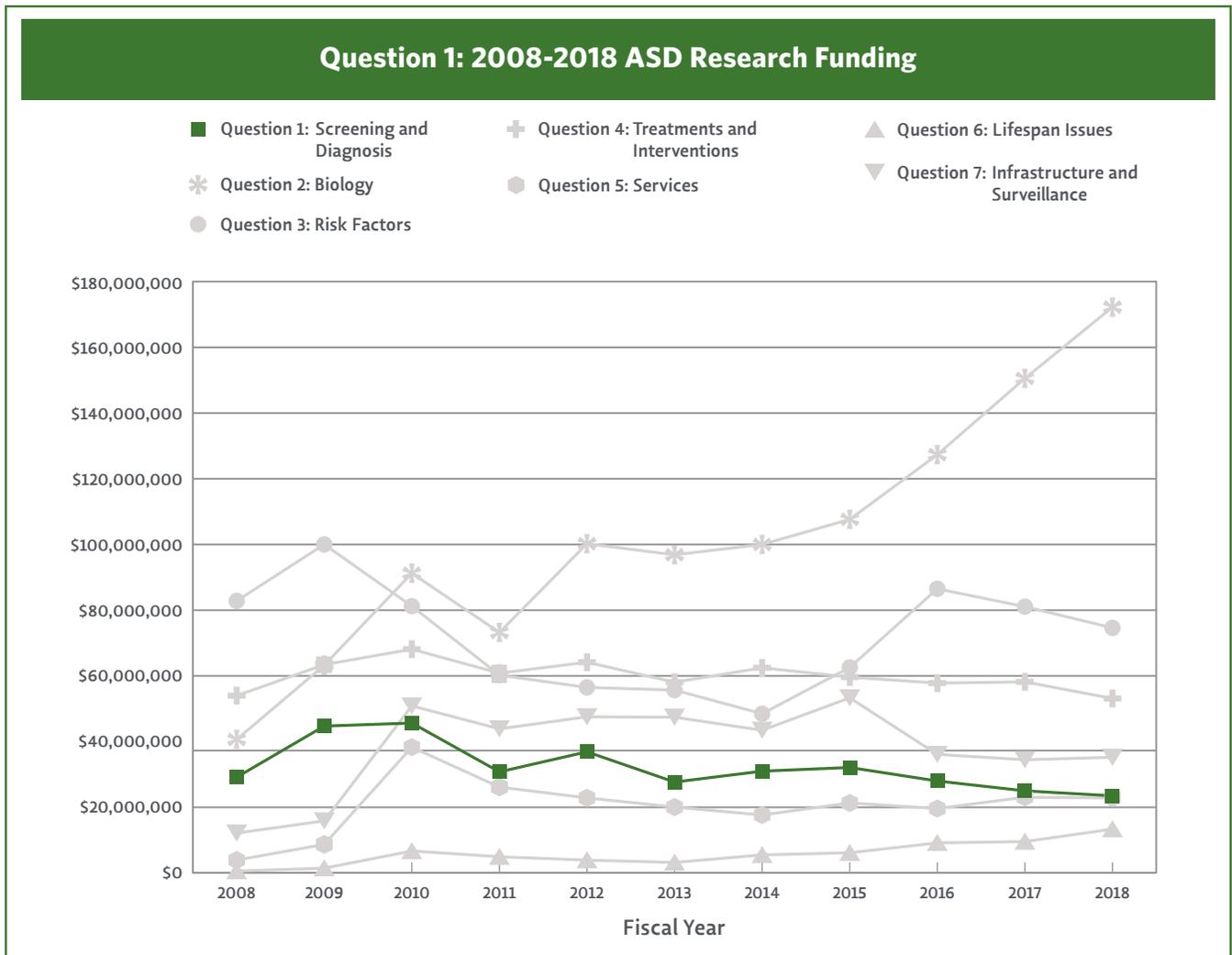


Figure 24. Question 1 ASD research funding from 2008-2018. Funding for Question 1 was moderate and stayed relatively flat over the eleven-year span.

ANALYSIS OF 2017-2018 QUESTION 2 PORTFOLIO

Among the seven Question areas described in the *IACC Strategic Plan*, Question 2 accounted for the largest portion of the ASD research portfolio in 2017 and 2018. Following similar trends as previous years, research on the biology of ASD (Question 2) comprised 39% of total funding (\$150.6 million) in 2017 and accounted for 44% (\$172.3 million) in 2018. Question 2 also had the largest portion of overall projects in 2017 (38%, 566 projects) and in 2018 (39%, 607 projects). Among federal agencies and private organizations, the National Institutes of Health provided the largest investment, contributing 83% of total Question 2 research funding in 2017 and 88% in 2018. The Simons Foundation was the next largest funder for Question 2 in both years. Research funding under Question 2 is categorized under three primary Objectives and one Cross-Cutting Objective. **Figures 25** and **26** provide a detailed overview of each Objective's total funding in 2017 and 2018 as well as the number of projects assigned to each Objective.

All three primary Objectives in Question 2 and the Cross-Cutting Objective received funding in 2017 and 2018. **Objective 2.1** had the most projects, with 73% of Question 2 funding (\$109.8 million) in 2017 and 74% (\$127.5 million) in 2018. Projects aligned to Objective 2.1 included 451 projects in 2017 and 477 projects in 2018. The aim of this Objective is to better understand the biological, molecular, and brain processes that contribute to ASD. The next largest portion of funding went to **Objective 2.3**,

which focuses on supporting large-scale longitudinal studies that assess the natural lifespan of ASD. In 2017, Objective 2.3 was 12% of Question 2 funding (\$17.6 million) and totaled 26 projects, and in 2018, it was 13% of Question 2 funding (\$22.6 million) with 33 projects. **Objective 2.2**, which emphasizes research in understanding co-occurring conditions, received \$12 million and accounted for 8% of Question 2 funding in 2017 (42 projects). In 2018, Objective 2.2 had 7% of Question 2 funding (\$12.2 million) and included 45 projects. The **Cross-Cutting Objective** (CC1) received 4% of funding (\$6.4 million; 25 projects) in 2017 under Question 2. Similarly, in 2018, 3% of Question 2 funding (\$4.4 million; 28 projects) aligned with the Cross-Cutting Objective. The goal for the Cross-Cutting Objective within Question 2 is to understand the biological basis of sex differences in ASD, such as differences in brain structure and functioning among girls and boys. In previous years, Question 2 had a large portion of its funding designated to Core/Other. In 2017 and 2018, only 3% of Question 2 funding was assigned to Core/Other (2017: \$4.8 million, 22 projects; 2018: \$5.7 million, 24 projects). Projects assigned to Core/Other included research studying the effects of exposure to environmental toxins on the development of the infant gut microbiome and the behavioral effects of fever on young children with autism.

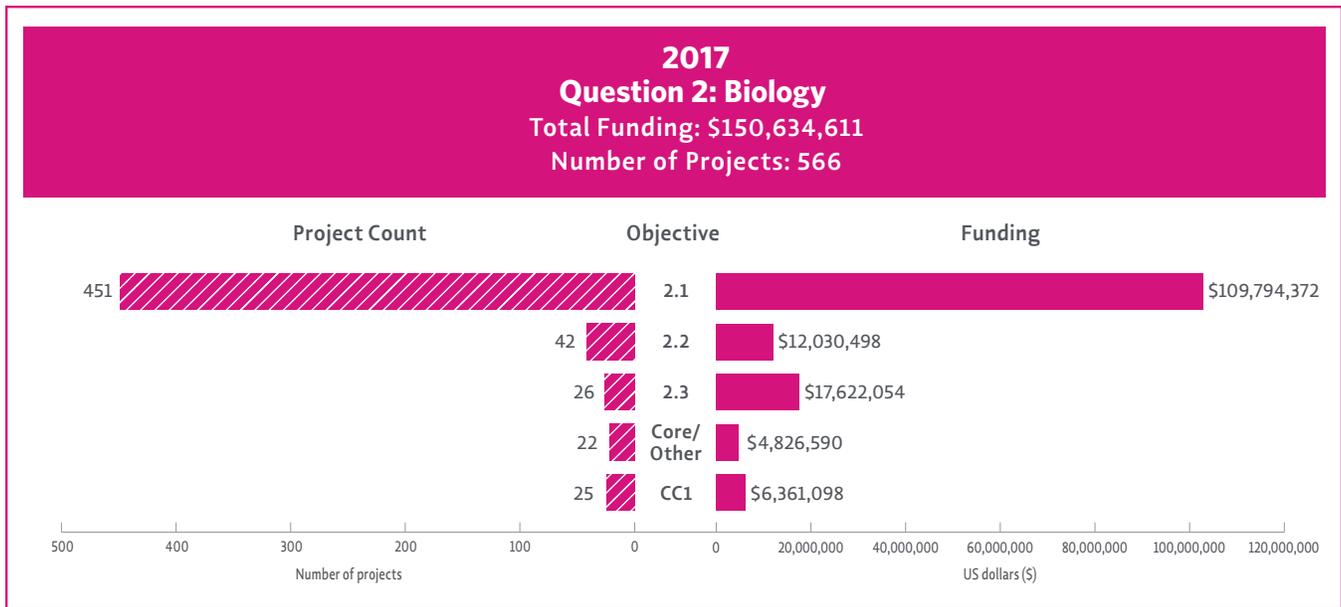


Figure 25. 2017 funding and project count by Question 2 Objectives. 2.1: Foster research to better understand the processes of early development, molecular and neurodevelopmental mechanisms, and brain circuitry that contribute to the structural and functional basis of ASD; 2.2: Support research to understand the underlying biology of co-occurring conditions in ASD and to understand the relationship of these conditions to ASD; 2.3: Support large-scale longitudinal studies that can answer questions about the development of ASD from pregnancy through adulthood and the natural history of ASD across the lifespan; Core/Other: Projects that do not align with Question 2 Objectives or support "core" activities in the autism research field; CC1: Support research to understand the underlying biology of sex differences in ASD, possible factors that may be contributing to under diagnosis, unique challenges that may be faced by girls/women on the autism spectrum, and develop strategies for meeting the needs of this population.

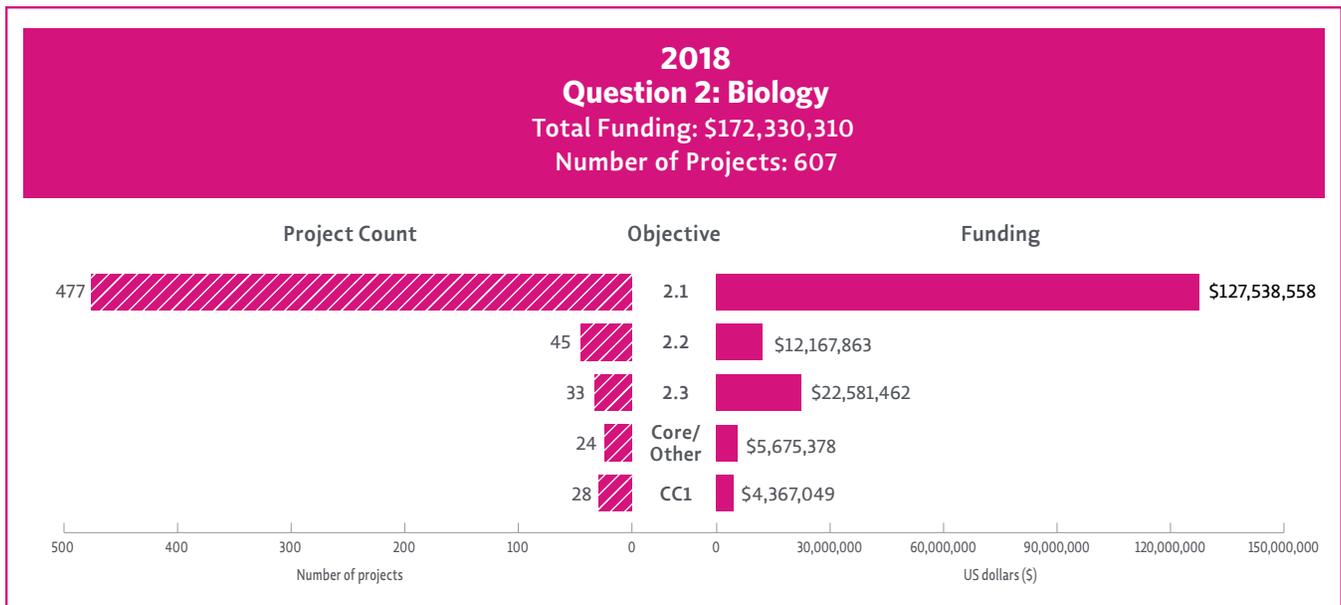


Figure 26. 2018 funding and project count by Question 2 Objectives. See Figure 25 caption above for descriptions of each Objective.

QUESTION 2 SUBCATEGORY ANALYSIS

The subcategory analysis is particularly useful for Question 2 in understanding the distribution of research on the underlying mechanisms of ASD. Research in this area covers a broad array of science, and, therefore, 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 27 and 28).

As in previous years, the Question 2 subcategory with the largest portion of funding in 2017 was **Molecular pathways** (33%, 205 projects), which includes projects seeking to understand systems of genes, proteins, and other molecules that are involved in ASD and related disorders. This trend held for 2018 as well, with Molecular pathways accounting for 34% of Question 2 funding and including 222 projects. Research exploring **Neural systems**, such as the structure of the brain and functional connections within the brain, was the second largest investment in both 2017 and 2018 (2017: 22%, 104 projects; 2018: 20%, 106 projects). Research into the **Developmental**

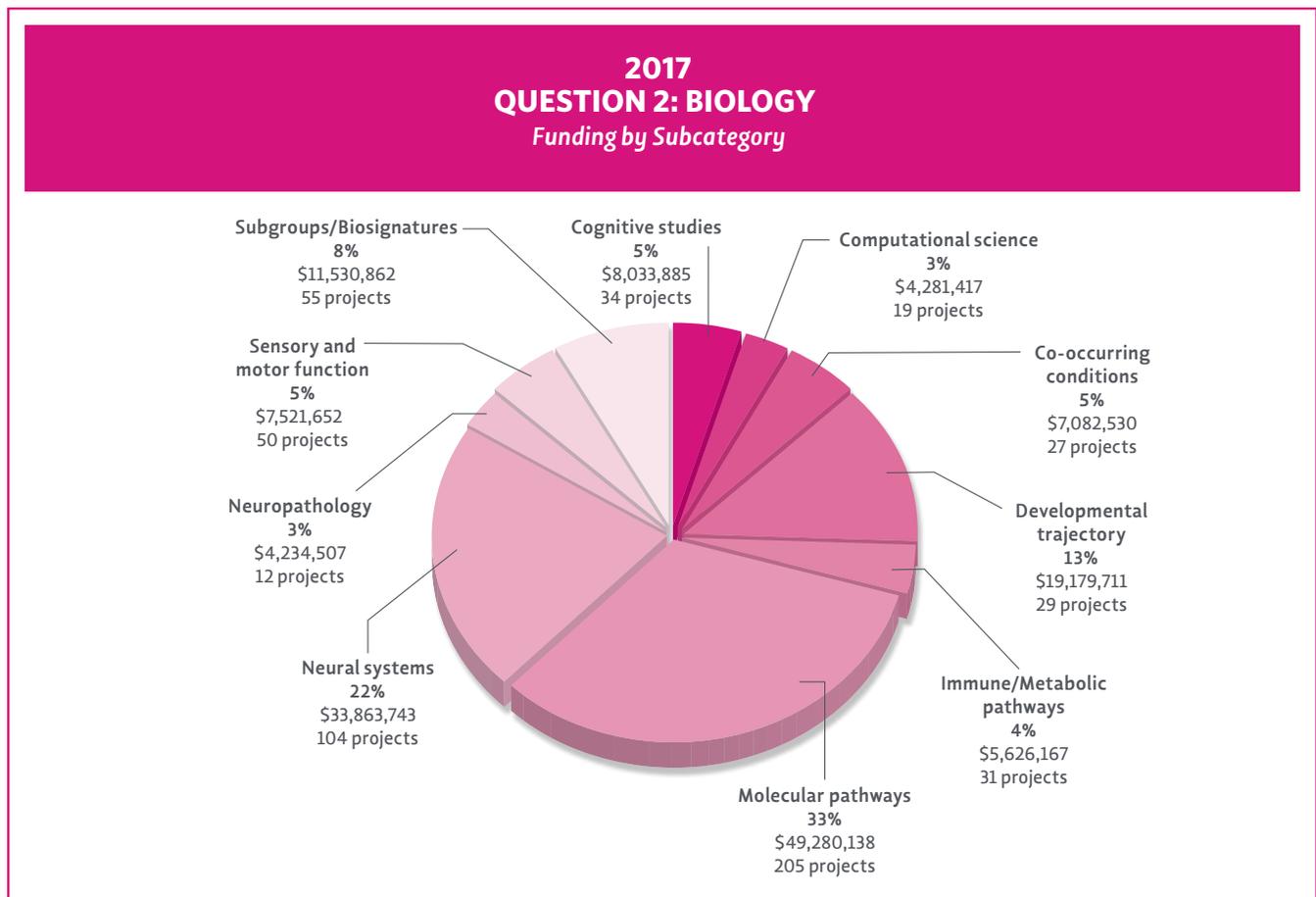


Figure 27. Question 2 funding by subcategory in 2017.

trajectory of ASD, including longitudinal studies that follow social, behavioral, and physical development over time, accounted for 13% (29 projects) of Question 2 funding in 2017 and 14% (33 projects) in 2018. The next largest subcategory focused on projects aiming to identify **Subgroups/Biosignatures** of ASD. In 2017, this subcategory accounted for 8% of Question 2 funding and 55 projects; in 2018, it received 10% of Question 2 funding and included 64 projects. In 2017, research investigating **Sensory and motor function**, **Cognitive studies**, and **Co-occurring conditions** each accounted for 5% of Question 2 funding (50, 34, 27 projects, respectively). Projects examining **Immune/**

Metabolic pathways received 4% of funding in 2017 (31 projects). Research in the areas of **Computational science** and **Neuropathology** each accounted for 3% of Question 2 funding in 2017 (19 and 12 projects, respectively). Comparably, in 2018, Sensory and motor function and Neuropathology each accounted for 5% of Question 2 funding (52 and 22 projects, respectively). Co-occurring conditions accounted for 4% of funding (35 projects). Cognitive studies also received 4% of Question 2 funding and contained 32 projects. This was followed by Immune/Metabolic pathways (2%, 25 projects) and Computational science (2%, 16 projects).

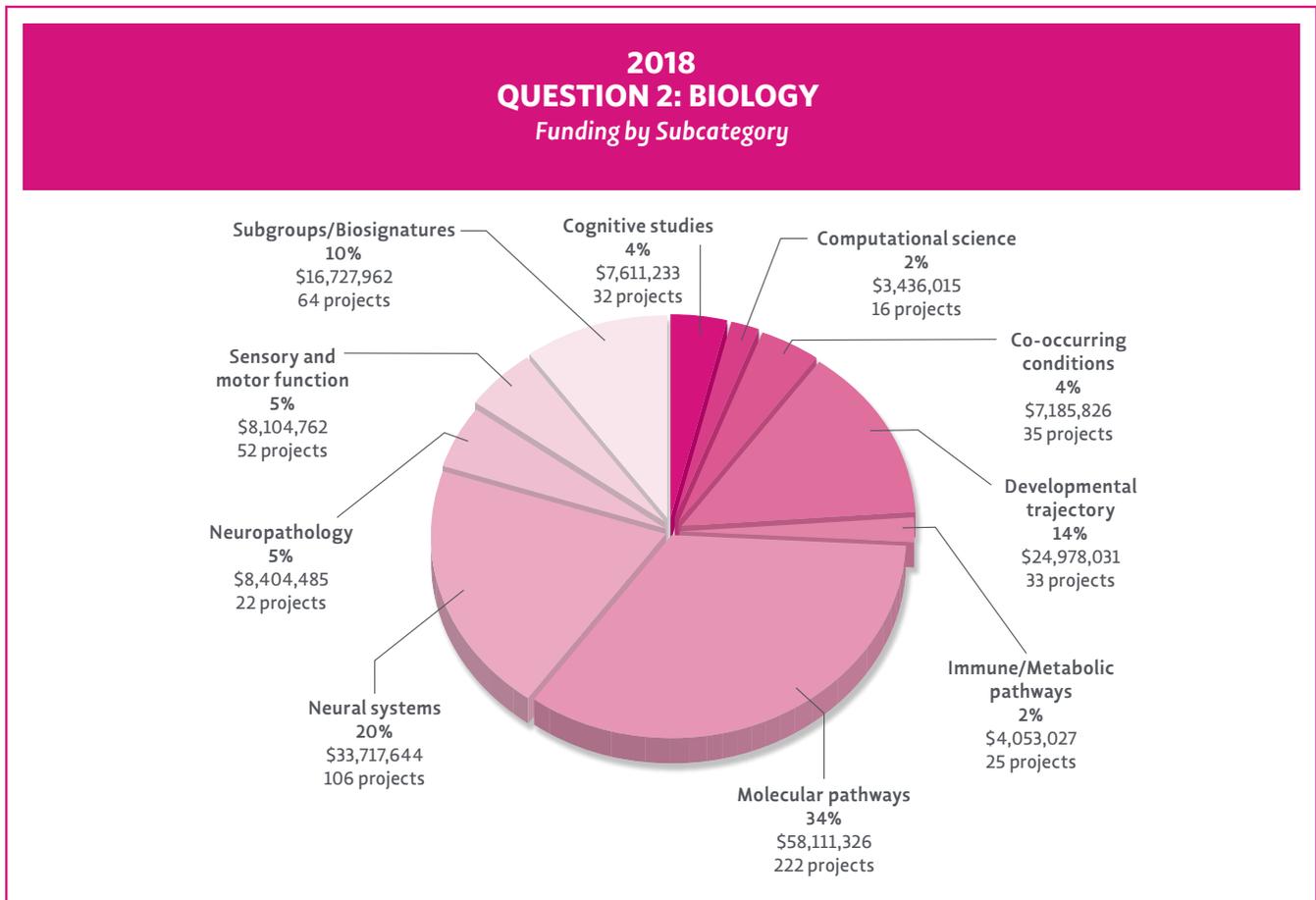


Figure 28. Question 2 funding by subcategory in 2018.

FUNDING PROGRESS MADE ON QUESTION 2 FROM 2008-2018

Figure 29 shows the trend in Question 2 funding 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 2008-2018, funding levels for this Question increased significantly in recent years. It is important to note that the 2016-2017 *Strategic Plan* Objectives led to the

reassignment of some projects from Question 4 to Question 2 Objectives based on the goals of the new Objectives; this may have contributed to the increase. However, Question 2 is the only Question area that has seen a significant increase in funding over the period from 2008-2018. Most of the other research areas remained relatively flat or decreased.

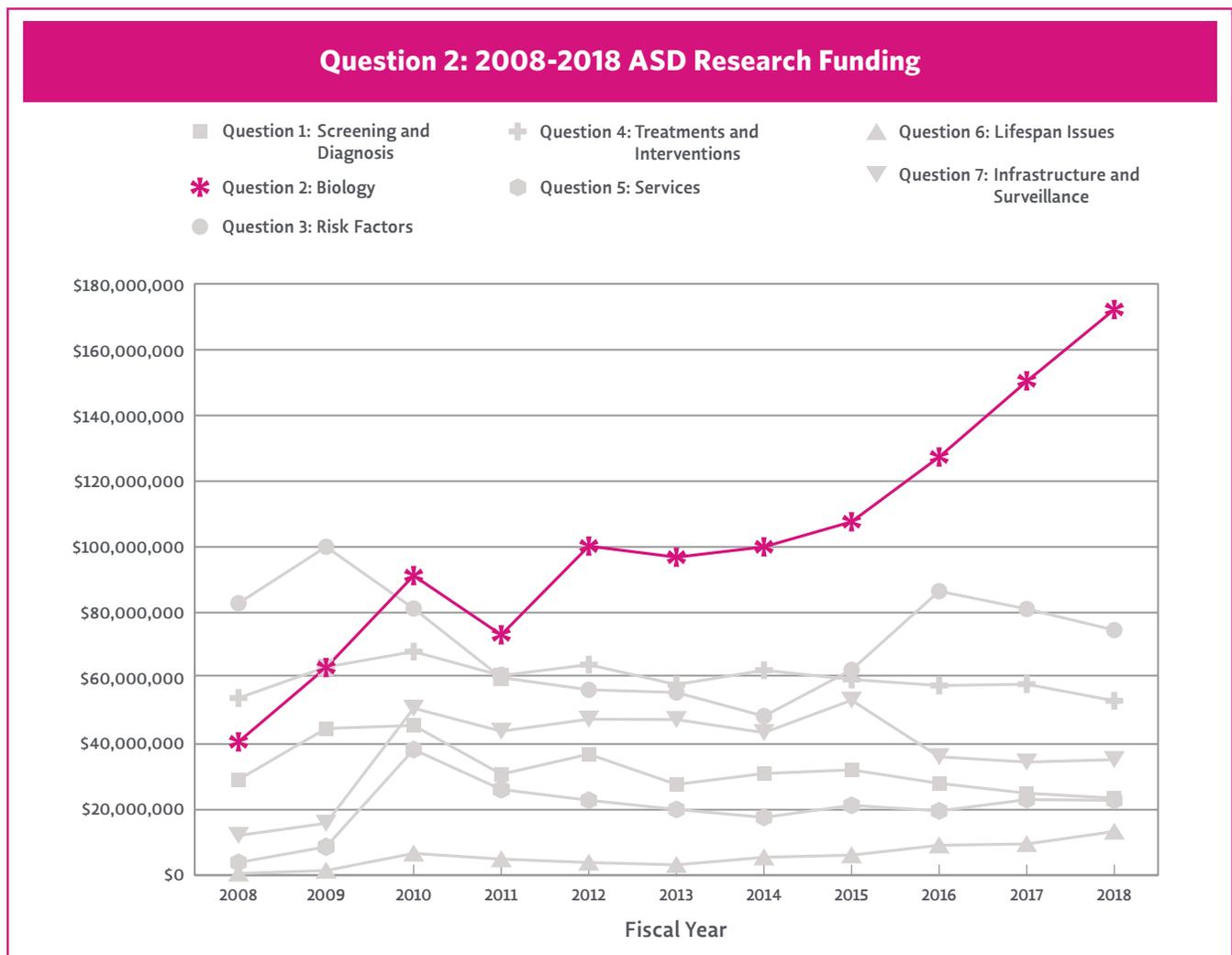


Figure 29. Question 2 ASD research funding from 2008-2018. Funding for Question 2 has experienced several substantial increases in funding over the eleven-year span, leading to a continual upward trend.

ANALYSIS OF 2017-2018 QUESTION 3 PORTFOLIO

In 2017, research on genetic and environmental factors associated with ASD (Question 3) accounted for \$81.1 million (21%) of total ASD research funding. A total of 261 projects were assigned to Question 3, which was 17% of all projects in the 2017 ASD portfolio. In 2018, Question 3 received 19% (\$74.7 million) of the portfolio's funding and included 249 projects (16% 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 primary Objectives and the Cross-Cutting Objective. **Figures 30** and **31** provide a detailed overview of each Objective's total funding in 2017 and 2018 as well as the number of projects assigned to each Objective.

Each Question 3 Objective received funding in 2017 and 2018. **Objective 3.1**, which identifies and strengthens the understanding of genetic factors that play a role in the development of ASD, received the largest proportion of funding. In 2017, Objective 3.1 received \$42.1 million, which was 52% of Question 3 funding, and included 153 projects. In 2018, Objective 3.1 accounted for 58% of Question 3 funding (\$43

million) and contained 153 projects. This was followed by **Objective 3.3**, which supports projects studying environmental and genetic exposures. Objective 3.3 accounted for 26% of Question 3 funding (\$20.7 million) and had 56 projects in 2017. In 2018, Objective 3.3 had 27% of funding (57 projects, \$19.9 million). In 2017, **Objective 3.2** (focused on environmental factors associated with ASD) received \$16.9 million and accounted for 21% of Question 3 funding (45 projects). In 2018, Objective 3.2 totaled \$10.7 million in research funding and was 14% of Question 3 funding (35 projects). The **Cross-Cutting Objective (CC1)** for Question 3, which investigates the genetic and/or environmental factors associated with sex differences in ASD, received \$0.9 million (1% of funding, 5 projects) in 2017 and \$1 million (1% of funding, 4 projects) in 2018. In 2017, Question 3 Core/Other had two projects that accounted for \$0.5 million and 1% of funding; these projects are studying the biological determinants of brain variation in ASD and child social attention and maternal synchrony during early parent-child interactions. 2018 did not include any projects under the Core/Other category.

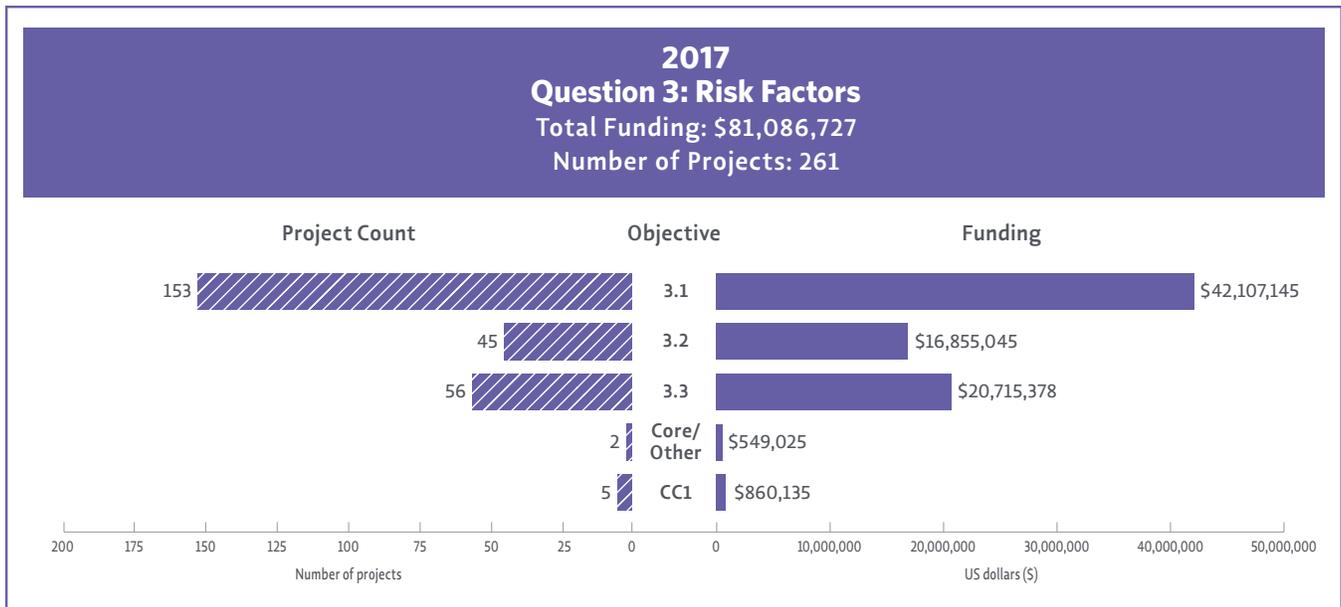


Figure 30. 2017 funding and project count by Question 3 Objectives. 3.1: Strengthen understanding of genetic factors for ASD across the full diversity and heterogeneity of those with ASD, enabling development of strategies for reducing disability and co-occurring conditions in ASD; 3.2: Understand the effects on ASD of individual and multiple exposures in early development, enabling development of strategies for reducing disability and co-occurring conditions in ASD; 3.3: Expand knowledge about how multiple environmental and genetic factors interact through specific biological mechanisms to manifest in ASD phenotypes; Core/Other: Projects that do not align with Question 3 Objectives or support "core" activities in the autism research field; CC1: Support research to understand the underlying biology of sex differences in ASD, possible factors that may be contributing to under diagnosis, unique challenges that may be faced by girls/women on the autism spectrum, and develop strategies for meeting the needs of this population.

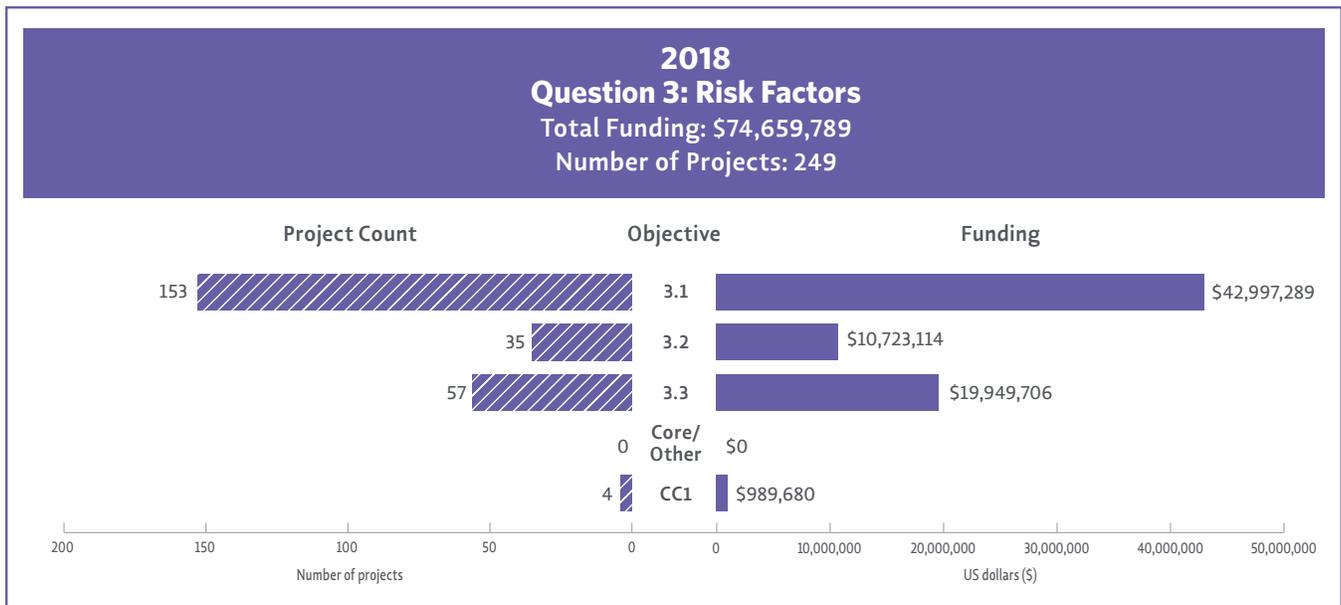


Figure 31. 2018 funding and project count by Question 3 Objectives. See Figure 30 caption above for descriptions of each Objective.

QUESTION 3 SUBCATEGORY ANALYSIS

Projects in Question 3 were divided into four subcategories to determine the funding distribution across the research areas relating to understanding and identifying genetic and environmental factors that play a role in the development of ASD. These subcategories include: **Environmental risk factors**; **Epigenetics**; **Gene-Environment**; and **Genetic risk factors** (Figures 32 and 33).

For both years of the portfolio analysis, studies focused on **Genetic risk factors** accounted for the highest percentage of Question 3 funding (2017: 52%, 158 projects; 2018: 57%, 152 projects). The next largest Question 3 subcategory investigates the role of environmental factors, genetic susceptibility, and/or the context of human physiology (**Gene-Environment**);

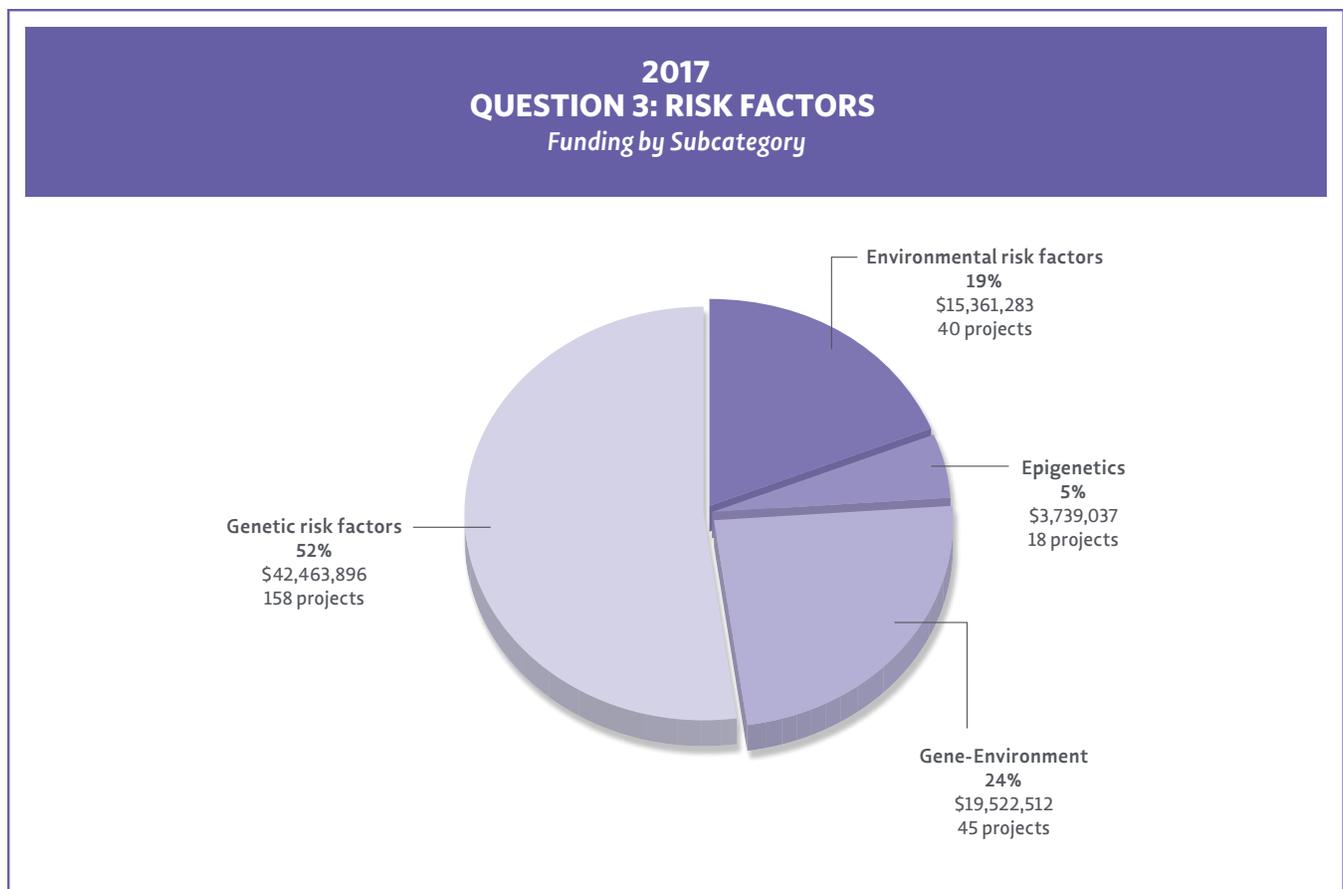


Figure 32. Question 3 funding by subcategory in 2017.

this subcategory received 24% of Question 3 funding and included 45 projects in 2017 and received 22% of funding and included 40 projects in 2018. Projects considering only **Environmental risk factors** received 19% of Question 3 funding in 2017 (40 projects). In 2018, this subcategory accounted for

14% of Question 3 funding and had 32 projects. Projects on **Epigenetics** received 5% of funding (18 projects) in 2017 and 7% of funding (25 projects) in 2018; these included studies investigating DNA modifications and exploring altered gene expression due to environmental influences.

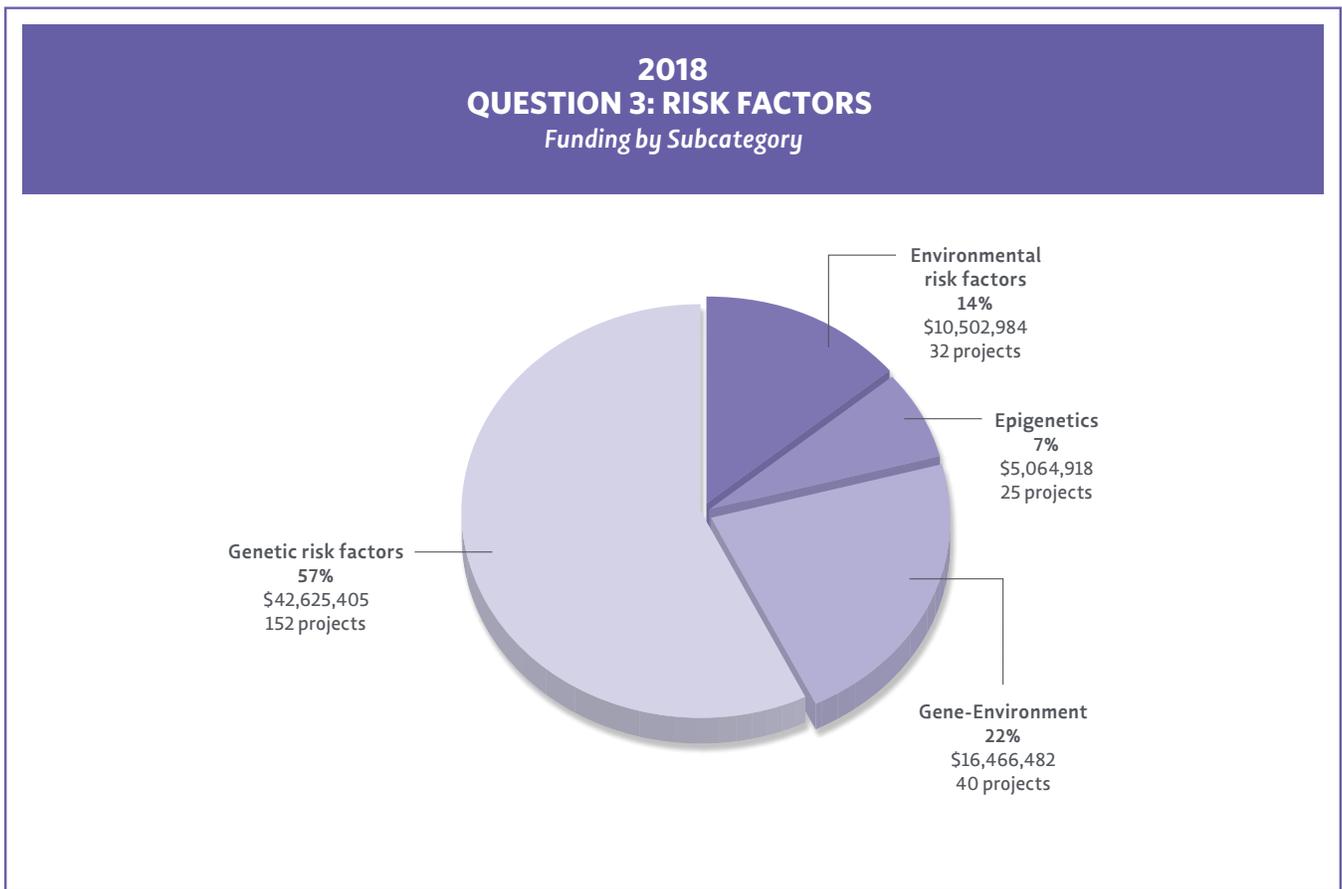


Figure 33. Question 3 funding by subcategory in 2018.

FUNDING PROGRESS MADE ON QUESTION 3 FROM 2008-2018

Figure 34 shows the trend in Question 3 funding over time. While research on risk factors remained funded at high levels over the eleven-year period compared to some of the other Question areas, Question 3 has experienced several fluctuations in funding throughout the years. The overall trend showed an initial increase in funding followed by a sharp decrease and then smaller

decreases in funding from 2011-2014. From 2014-2016 there was a significant increase. The increase in 2016, due in part to reassignment of SPARK genetics projects to a new Objective within Question 3, has brought Question 3 funding in 2016 to levels comparable with 2008 funding, though funding levels have decreased slightly in both 2017 and 2018.

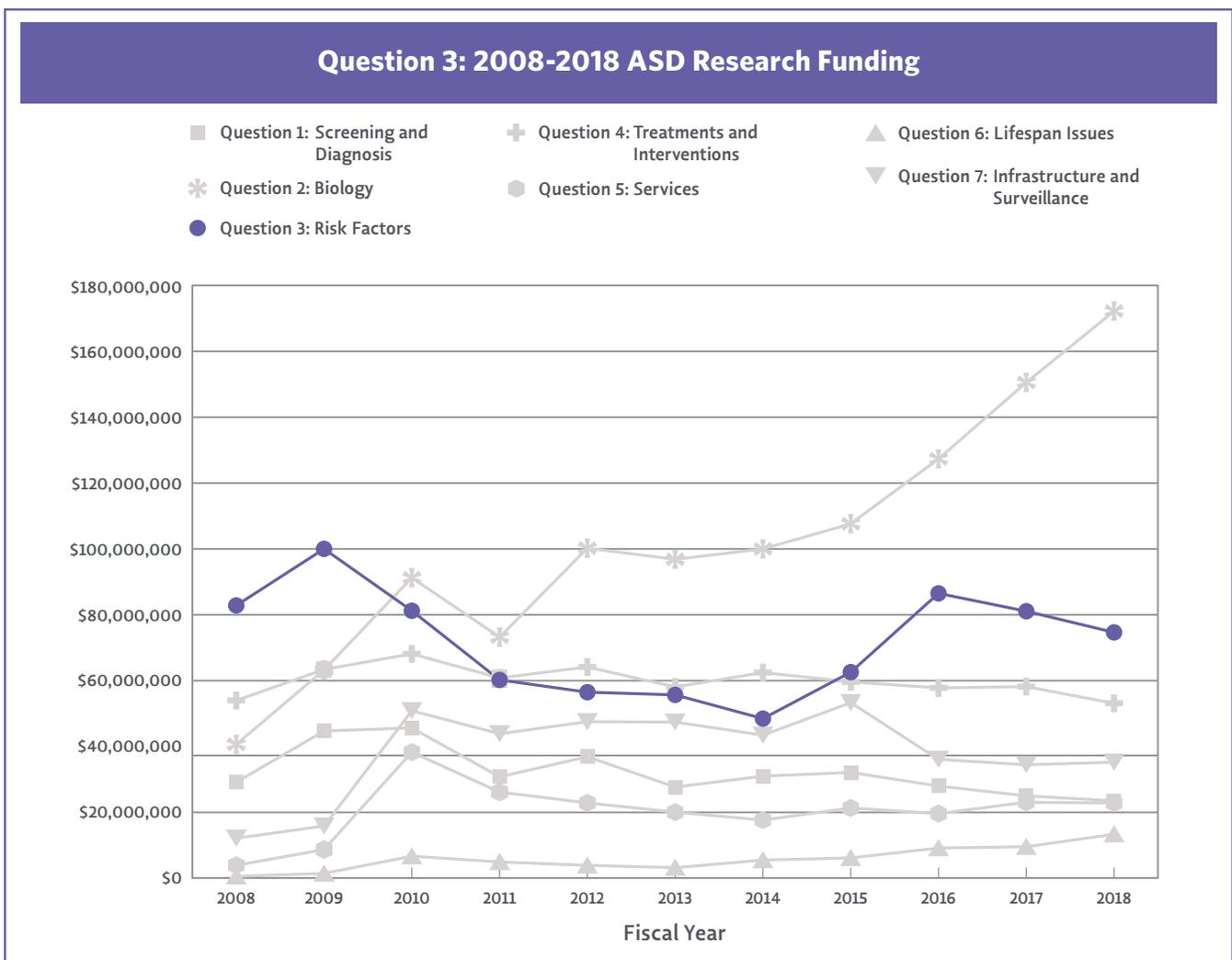


Figure 34. Question 3 ASD research funding from 2008-2018. Over the eleven-year span, funding for Question 3 initially showed an increase followed by a sharp decrease, then a gradual decrease, a rapid increase from 2014-2016, and finally a slight decrease between 2016 and 2018.

ANALYSIS OF 2017-2018 QUESTION 4 PORTFOLIO

Research focused on interventions and treatments received \$58.2 million (15%) of total ASD funding in 2017. The number of projects assigned to Question 4 totaled 273 projects, which was 18% of all projects included in the portfolio. In 2018, funding towards Question 4 accounted for 13% of the portfolio (\$52.5 million) and 17% of total projects (264 projects). Many agencies and organizations invest in treatments and interventions; however, the funders with the largest contributions during this period were the National Institutes of Health, the Department of Defense - Army, the Health Resources and Services Administration, and the Department of Education. Question 4 has three primary Objectives and the Cross-Cutting Objective. **Figures 35** and **36** provide a detailed overview of each Objective's total funding and the number of projects assigned to each Objective in 2017 and 2018.

Every Objective in Question 4 as well as the Cross-Cutting Objective had assigned projects or funding for both years of the portfolio analysis; however, there were differences in funding levels among the Objectives for 2017 and 2018. The Question 4 Objective receiving the most funding in 2017, **Objective 4.2**, focuses on the development of psychosocial and naturalistic interventions (\$26.4 million, 45%); this Objective also had the largest number of projects in 2017 (124 projects). Objective 4.2 was the second largest funded Objective in 2018; it accounted for 34% of Question 4 funding (\$17.9 million) and included 120 projects. **Objective 4.1** received 42% of 2017's Question

4 funding with \$24.2 million and 84 projects; this Objective includes research on pharmacological and medical interventions. Objective 4.1 received the most funding in 2018, accounting for 49% of Question 4's funding (\$25.9 million) and 85 projects. The increase in funding for Objective 4.1 in 2018 included large grants for the National Institutes of Health's Autism Biomarkers Consortium for Clinical Trials and the Health Resources and Services Administration's Autism Intervention Research Network on Physical Health (AIR-P network). **Objective 4.3** received the lowest levels of funding each year, with the goal to optimize development of technology-based interventions; it received \$5.7 million (10%) and had 53 projects in 2017 and \$7.3 million (14%) and had 50 projects in 2018. The aim of the **Cross-Cutting Objective** (CC1) within Question 4 is to investigate treatment/intervention response based on sex differences and explore the development of interventions that address sex differences. In 2017, funding for projects associated with the Cross-Cutting Objective totaled \$180,000 (<1%, 2 projects); in 2018, one of these projects was considered ongoing but did not receive any further funding. The rest of Question 4 funding went to projects categorized as Core/Other, which accounted for \$1.6 million (3%) and 10 projects in 2017 and \$1.5 million (3%) and eight projects in 2018. Projects assigned to Core/Other included parent training interventions and assessing brain imaging markers in response to interventions in toddlers with autism.

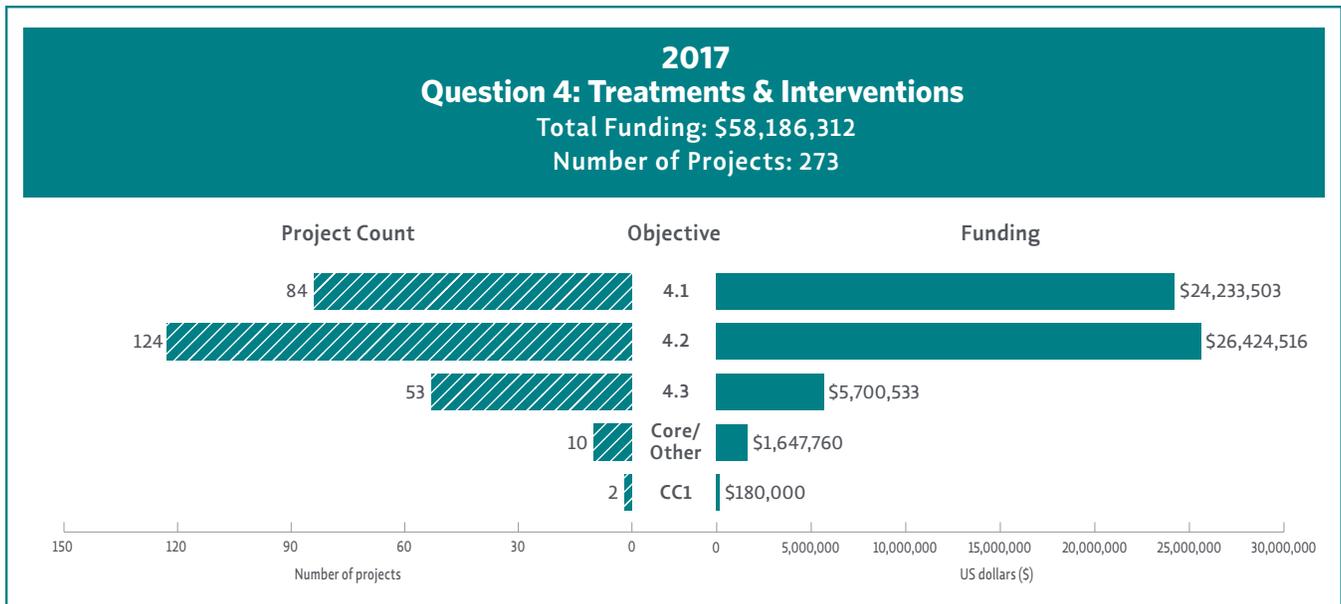


Figure 35. 2017 funding and project count by Question 4 Objectives. 4.1: Foster research to better understand the processes of early development, molecular and neurodevelopmental mechanisms, and brain circuitry that contribute to the structural and functional basis of ASD; 4.2: Support research to understand the underlying biology of co-occurring conditions in ASD and to understand the relationship of these conditions to ASD; 4.3: Support large-scale longitudinal studies that can answer questions about the development of ASD from pregnancy through adulthood and the natural history of ASD across the lifespan; Core/Other: Projects that do not align with Question 4 Objectives or support "core" activities in the autism research field; CC1: Support research to understand the underlying biology of sex differences in ASD, possible factors that may be contributing to under diagnosis, unique challenges that may be faced by girls/women on the autism spectrum, and develop strategies for meeting the needs of this population.

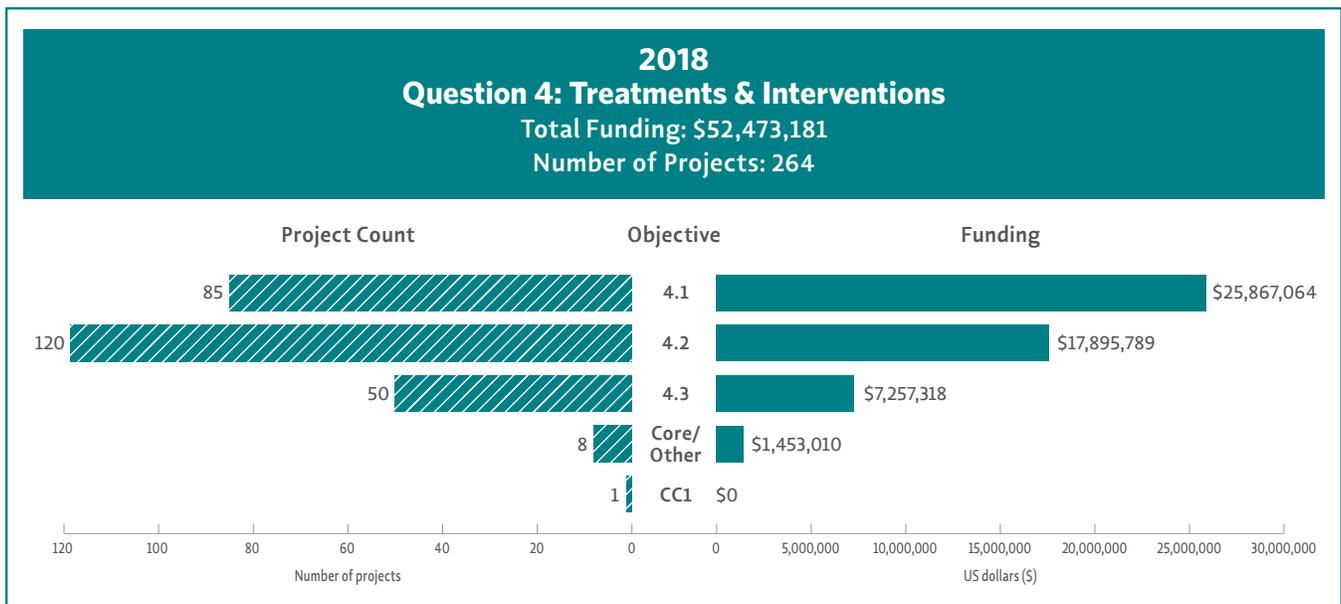


Figure 36. 2018 funding and project count by Question 4 Objectives. See Figure 35 caption above for descriptions of each Objective.

QUESTION 4 SUBCATEGORY ANALYSIS

Question 4 represents research on a wide array of treatments and interventions for ASD, ranging from medications to alleviate core and co-occurring conditions, to behavioral therapies and technologies to improve communication, social skills, life skills, and learning. Projects under Question 4 were broken down into these 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 37 and 38).

The subcategories for Question 4 illustrate the many approaches to treatments and interventions supported by autism research funders. In 2017 and 2018, the largest amount of funding supported projects to develop **Behavioral** interventions (2017: 35%, 102 projects; 2018: 24%, 87 projects), including applied behavior analysis (ABA), cognitive therapy, and social skills training. In 2017, research on **Model systems/Therapeutic targets** (23%, 33 projects) followed, focusing on early development of animal and cellular models that mimic characteristics of ASD to test experimental therapies. This subcategory was the third highest funded area in 2018 (22%, 32 projects).

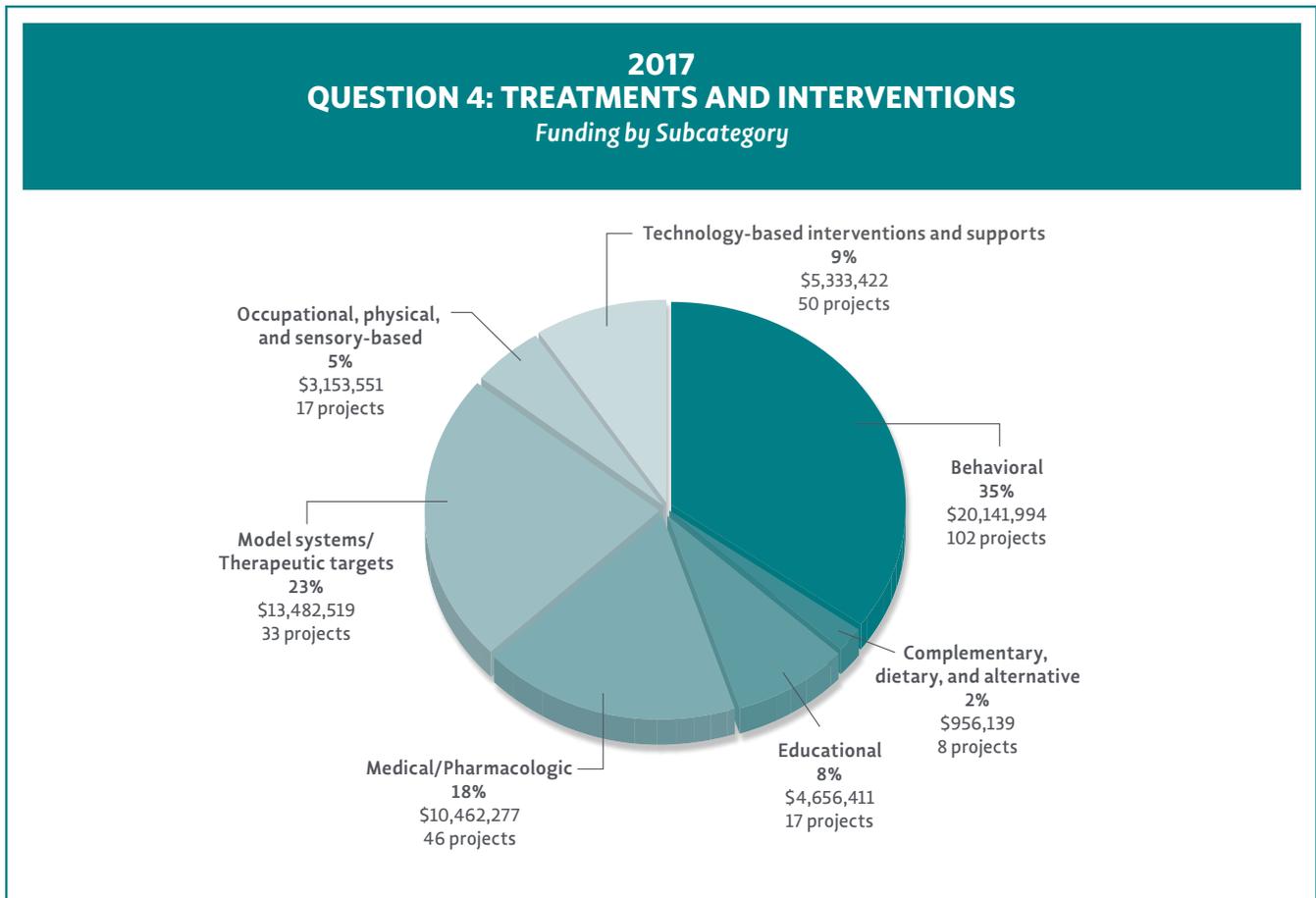


Figure 37. Question 4 funding by subcategory in 2017.

As described in the 2016 IACC Portfolio Analysis Report, Objectives experienced a shift in the categorization of some projects using ASD 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 treatments remain in Question 4. The next largest subcategory in 2017 was **Medical/Pharmacologic** interventions, which received 18% of funding (46 projects). In 2018, this subcategory was the second largest funded research area, with 22% of Question 4 funding and 48 projects. As mentioned

in the previous section, there were several large grants funded in 2018 focused on improving pharmacological and medical interventions and treatments. **Technology-based interventions and supports** received 9% of funding (50 projects) in 2017 and 14% of funding in 2018 (51 projects). For both years, **Educational** (classroom-based) interventions received 8% of funding (17 projects in 2017, 21 projects in 2018). The subcategories with the smallest amounts of funding included **Occupational, physical, and sensory-based** (2017: 5%, 17 projects; 2018: 7%, 16 projects) and **Complementary, dietary, and alternative** interventions (2017: 2%, 8 projects; 2018: 3%, 9 projects).

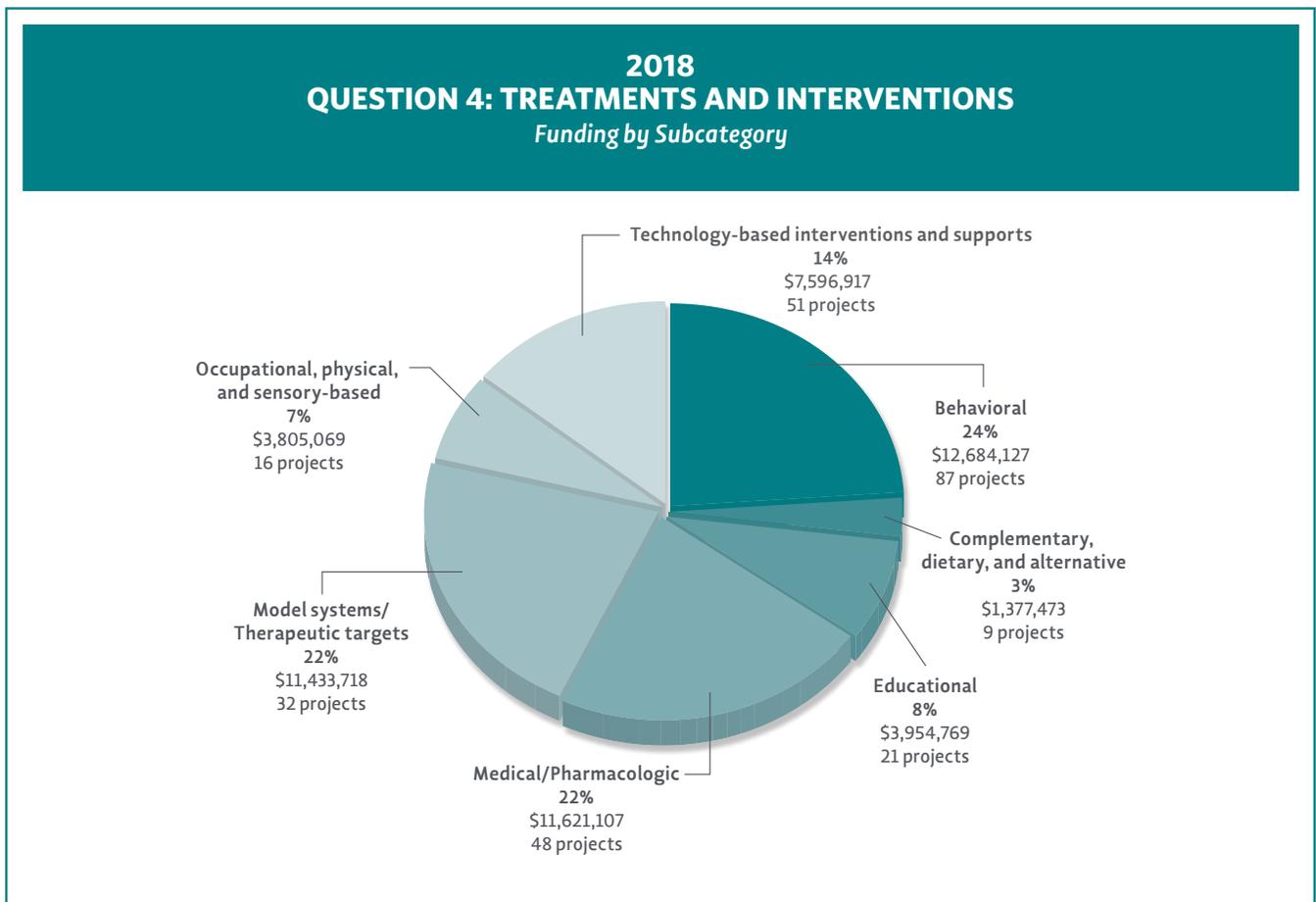


Figure 38. Question 4 funding by subcategory in 2018.

FUNDING PROGRESS MADE ON QUESTION 4 FROM 2008-2018

The trend in annual Question 4 funding over time is shown in **Figure 39**. Overall, research funding focused on treatments and interventions maintained a steadily moderate level over the eleven-year time span.

Question 4 has consistently had one of the largest proportions of funding compared to other Question areas.

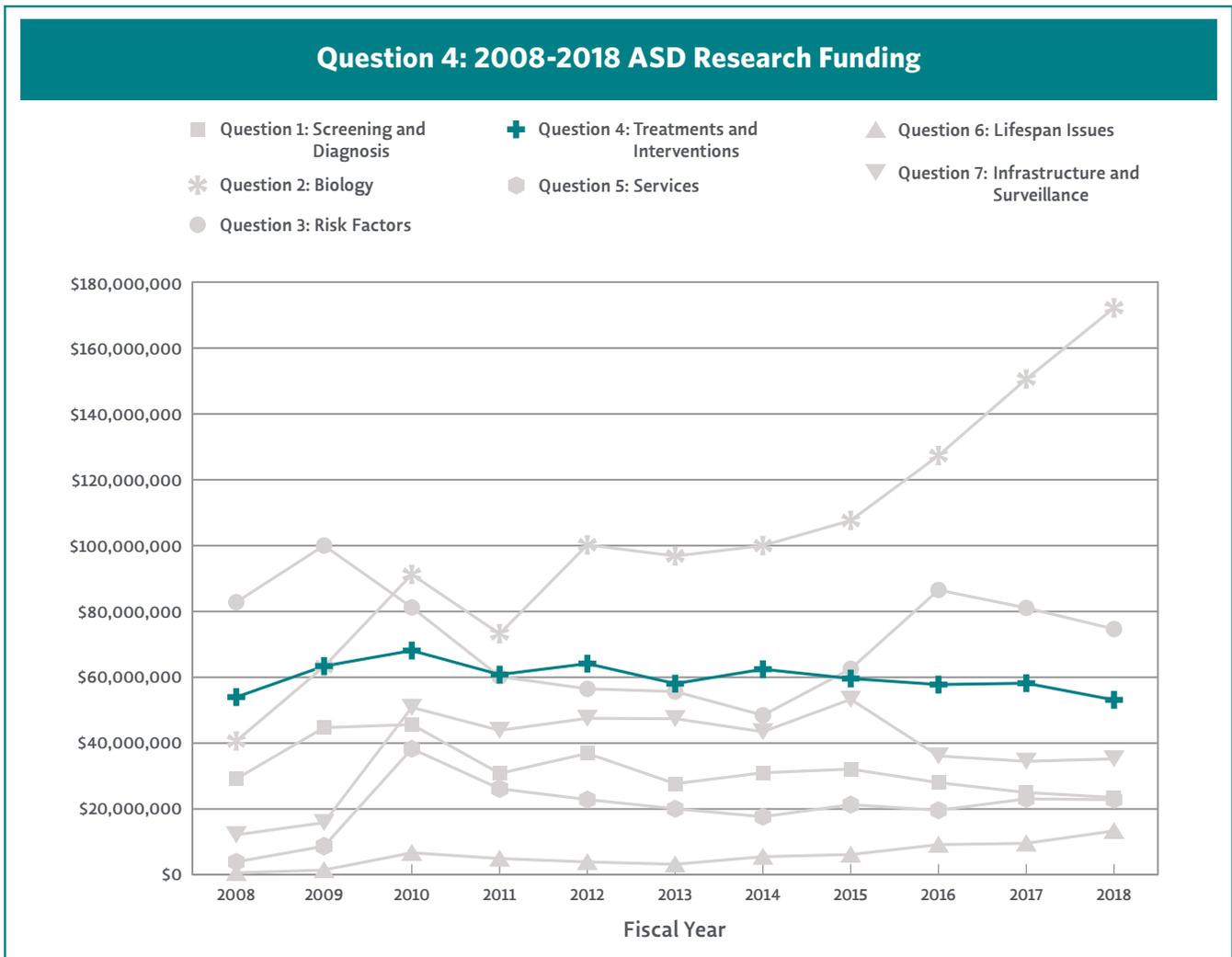
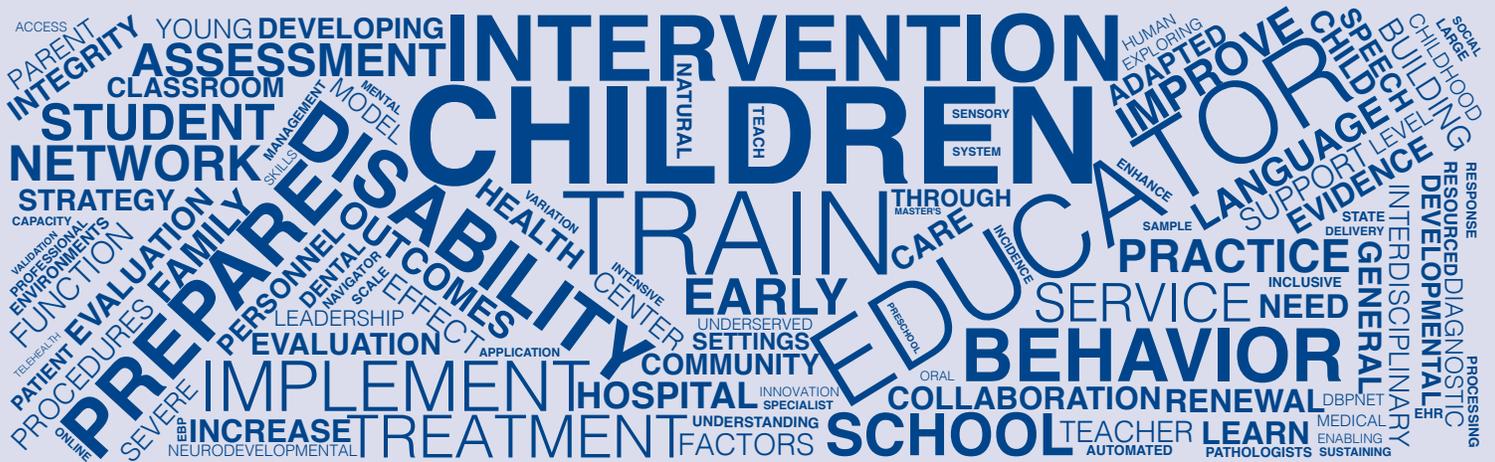


Figure 39. Question 4 ASD research funding from 2008-2018. Funding for Question 4 remained primarily flat, but relatively robust, over the eleven-year span.




Question 5 SERVICES

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 with ASD 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 on services and supports for people with ASD. 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 ASD service 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 with ASD, particularly identifying culturally appropriate best practices.

ANALYSIS OF 2017-2018 QUESTION 5 PORTFOLIO

Projects assigned to Question 5 comprised 6% of the total ASD research supported in 2017 (\$23 million) and consisted of 118 projects, which was 8% of the total number of ASD projects. Similarly, Question 5 accounted for 6% of 2018's research portfolio (\$22.8 million) and included 114 projects (7%). The largest funders of Question 5 were the National Institutes of Health, Department of Education, and Centers for Disease Control and Prevention. Question 5 consists of three primary Objectives and the Cross-Cutting Objective. **Figures 40** and **41** provide a detailed overview of each Objective's total funding in 2017 and 2018 as well as the number of projects assigned to each Objective.

All three primary Objectives in Question 5 received funding in 2017 and 2018. The majority of projects that were categorized under this Question went towards **Objective 5.3**, which supports developing and improving service models to improve the quality of care individuals receive from ASD services. Objective 5.3 was 62% of the 2017 Question 5 portfolio, receiving \$14.3 million in funding and included 76 projects. In 2018, Objective 5.3 accounted for 61% of Question 5's funding (\$14 million) and included 78 projects. The next largest portion of 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 \$8.1 million (35%) in 2017 and had 30 projects; in 2018, this Objective totaled \$7.7 million (34%) and had 25 projects. **Objective 5.2**, research focused on reducing the disparities in access to services for underserved populations, followed with \$0.2 million and 1% of Question 5 funding for both 2017 and 2018 (7 projects in 2017, 9 projects in 2018). In 2017, Question 5 Core/Other received 2% of Question 5 funding, with nearly \$400,000 and five projects. In 2018, Question 5 Core/Other included 4% of total Question 5 funding (\$875,000) and two projects. Projects assigned to Core/Other included developing and testing an incident alert system to be used with law enforcement officials and caregivers as well as training for professionals in specialized education. The **Cross-Cutting Objective** (CC1) which focuses on sex differences in ASD did not receive any Question 5 funding in 2017 or 2018. Future projects that would potentially fit in the Cross-Cutting Objective within Question 5 include studies of differences in services and supports needs based on sex and gender.

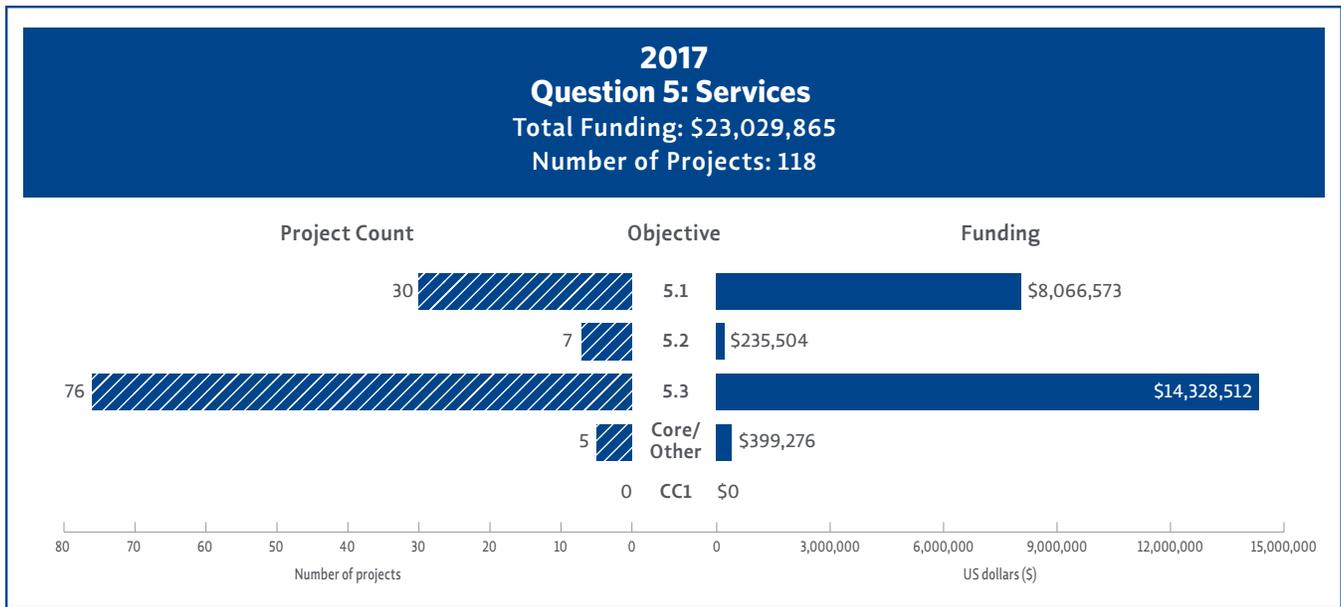


Figure 40. 2017 funding and project count by Question 5 Objectives. 5.1: Scale up and implement evidence-based interventions in community settings; 5.2: Reduce disparities in access and in outcomes for underserved populations. 5.3: Improve service models to ensure consistency of care across many domains with the goal of maximizing outcomes and improving the value that individuals get from services; Core/Other: Projects that do not align with Question 5 Objectives or support "core" activities in the autism research field; CC1: Support research to understand the underlying biology of sex differences in ASD, possible factors that may be contributing to under diagnosis, unique challenges that may be faced by girls/women on the autism spectrum, and develop strategies for meeting the needs of this population.

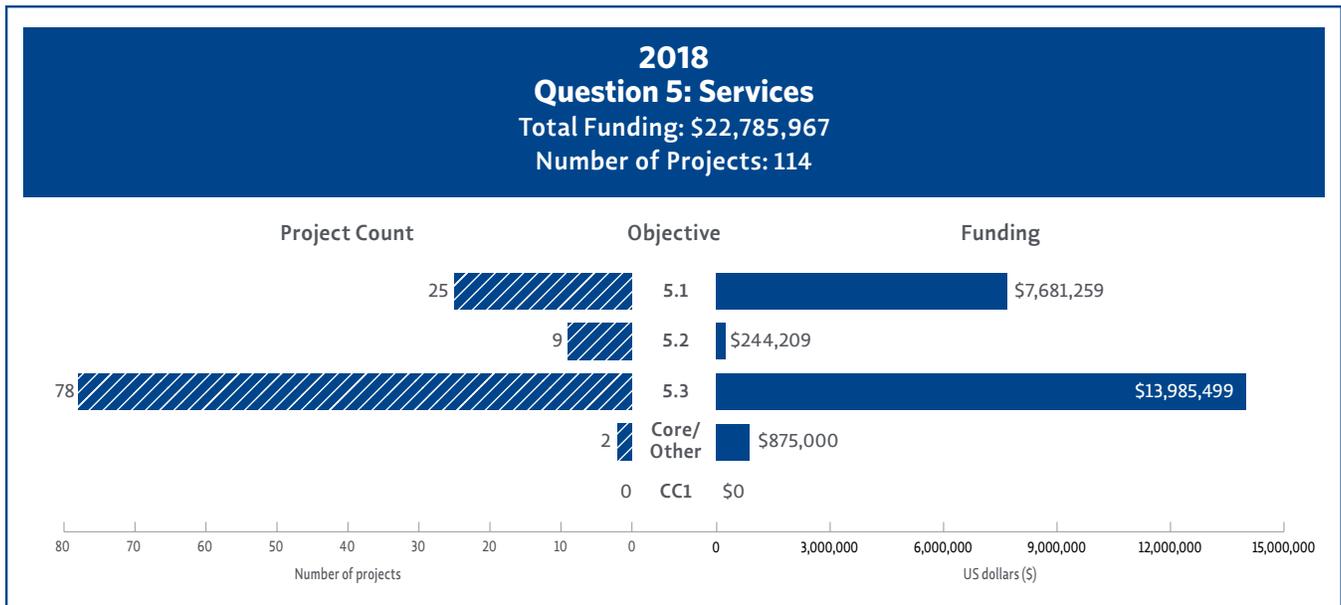


Figure 41. 2018 funding and project count by Question 5 Objectives. See Figure 40 caption above for descriptions of each Objective.

QUESTION 5 SUBCATEGORY ANALYSIS

Projects within Question 5 have been categorized into five subcategories which 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 42 and 43).**

In 2017 and 2018, research concerning the development and evaluation of **Practitioner training,** largely represented in the Health Resources and Services Administration’s **Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs,** accounted for the majority of Question 5 funding (2017: 44%, 58 projects; 2018: 46%, 58 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

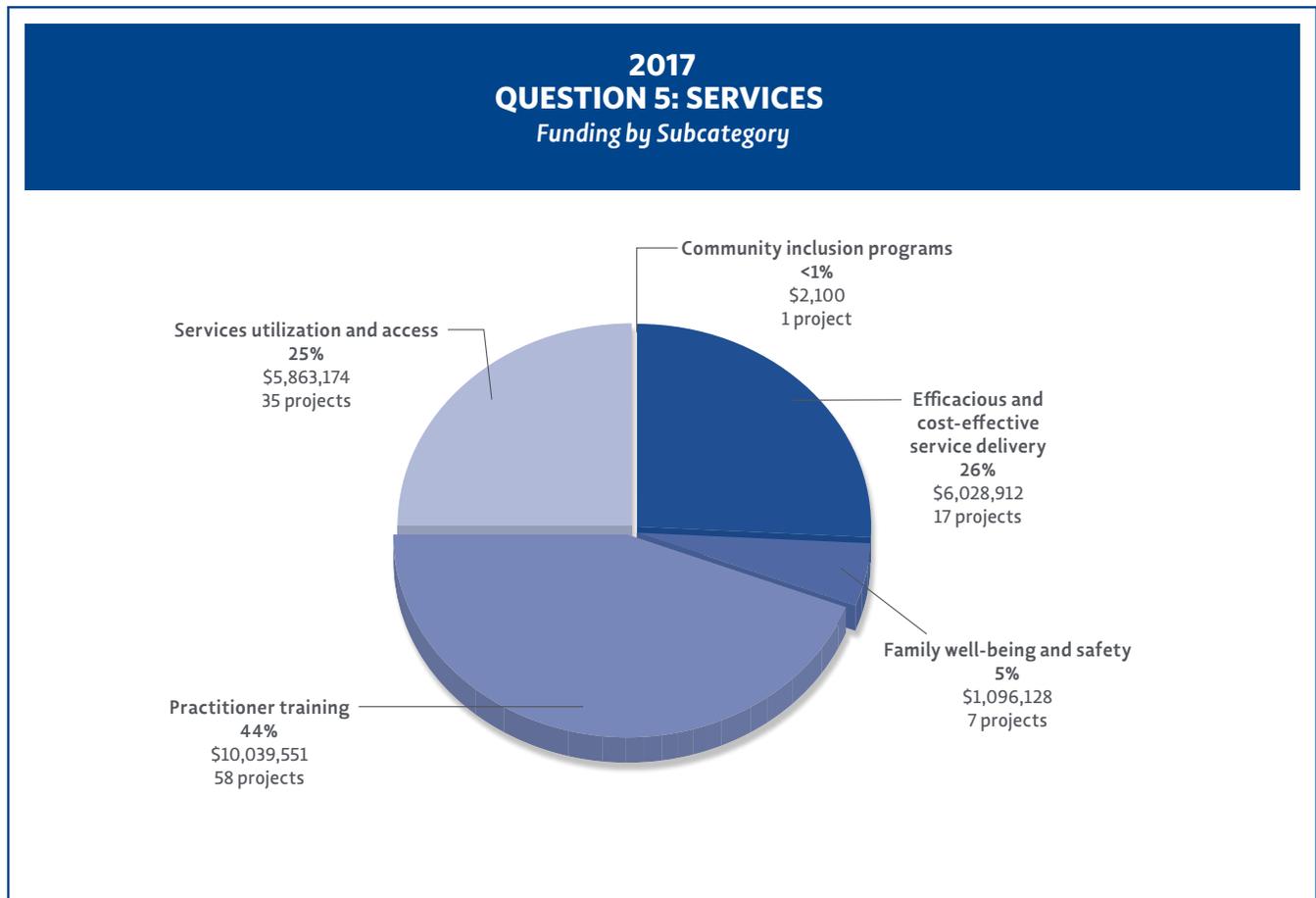


Figure 42. Question 5 funding by subcategory in 2017.

of providing services, aligned with 26% of Question 5 funding (17 projects) in 2017 and 20% of funding in 2018 (19 projects). Research focused on disparities and potential barriers to access are covered in **Services utilization and access** and accounted for 25% of Question 5 funding in 2017 (35 projects) and 32% in 2018 (33 projects). Funding for this subcategory saw a significant increase in funding from 2016, when it was only 2% of Question 5 funding and seven projects. This research area saw several large projects funded in 2017 and 2018 by the National Institutes of Health focused

on implementing evidence-based interventions in real-world settings. **Family well-being and safety** research projects followed with 5% of 2017 funding (7 projects) and 3% of 2018 Question 5 funding (3 projects). One project was categorized as **Community inclusion programs** and received less than 1% of 2017 funding and received no funding in 2018 (the project funded in 2017 received all of its funding in 2017 and the work continued into 2018 without additional funding).

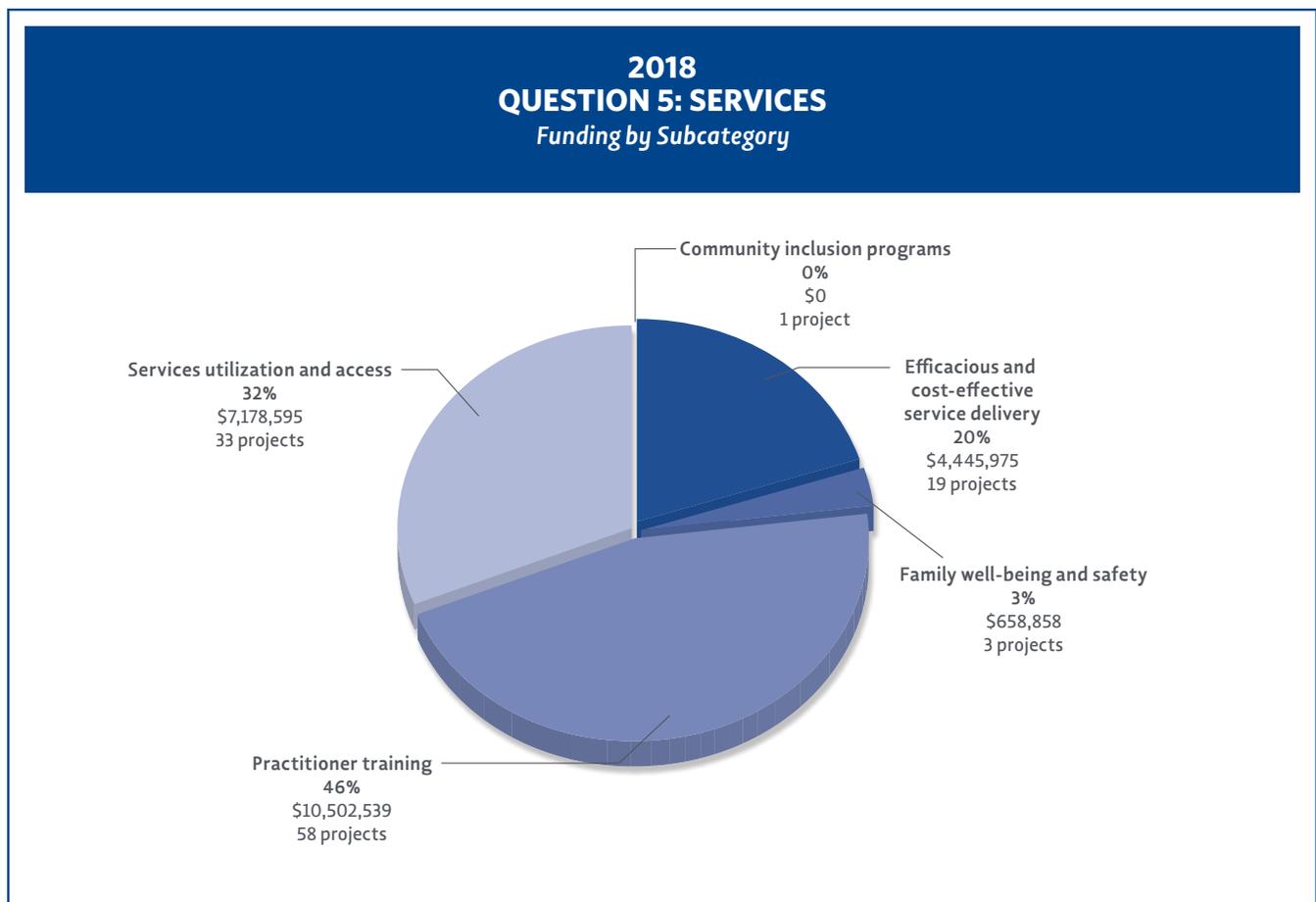


Figure 43. Question 5 funding by subcategory in 2018.

FUNDING PROGRESS MADE ON QUESTION 5 FROM 2008-2018

Figure 44 shows the trend in Question 5 funding over time. Research related to Question 5 was funded at relatively low levels when compared to other Question areas. Funding for projects within Question 5 appeared

to decrease after 2010.* Overall, when comparing 2008 funding for Question 5 with 2018 funding, the general trend is upward. In recent years, funding has stayed consistent.

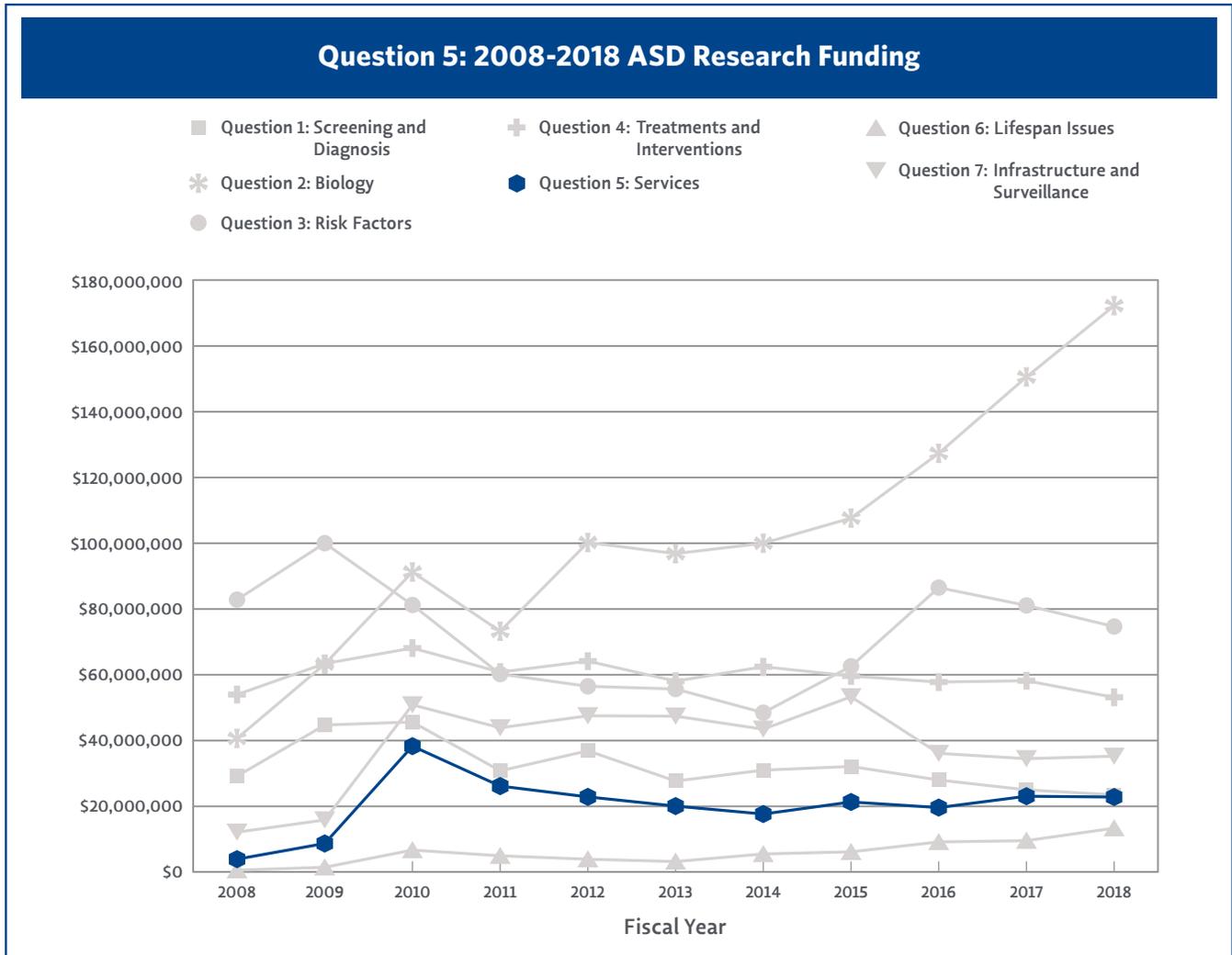


Figure 44. Question 5 ASD research funding from 2008-2018. Compared to other *Strategic Plan* Questions, funding for Question 5 remained relatively low over the eleven-year span.

* 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. The figure displays the Question 5 funding in 2010 using the criteria that were applied in later years 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.

ANALYSIS OF 2017-2018 QUESTION 6 PORTFOLIO

In 2017, research on lifespan issues associated with ASD (Question 6) accounted for 2% (\$9.5 million) of total ASD research funding and included 65 projects (4% of total projects). In 2018, Question 6 totaled 3% of the portfolio's funding (\$13.3 million) and contained 80 projects (5% of all projects). 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 stakes in this research in 2017 were the National Institutes of Health, the New Jersey Governor's Council for Medical Research and Treatment of Autism (which is included for the first time in the *IACC Portfolio Analysis Report*), and the National Science Foundation. In 2018, the top three funders of Question 6 research were the National Institutes of Health, Department of Defense - Army, and the Administration for Community Living. As mentioned in an earlier section of this report, Question 6 saw the largest proportion of funding for new projects; furthermore, the interest of diverse funders in this topic demonstrates the community's growing commitment to support research in this area. Question 6 has three primary Objectives and the Cross-Cutting Objective. **Figures 45** and **46** provide a detailed overview of each Objective's total funding as well as the number of projects assigned to each Objective.

For both 2017 and 2018, all three primary Objectives and the Cross-Cutting Objective assigned to Question 6 received funding. The largest portion of funding went to research supporting the transition to adulthood; **Objective 6.1** accounted for 62% of Question 6 funding in 2017, which totaled \$5.9 million and 35 projects. In 2018, Objective 6.1 was 63% of Question 6 funding (\$8.4 million) and supported 41 projects. In 2017, **Objective 6.2** received \$2.5 million (26%) and included 10 projects; the goal of this Objective is to conduct research to enhance quality of life and reduce the disabling effects of co-occurring conditions. In 2018, Objective 6.2 received \$1.6 million (12%) and contained 15 projects. Research focused on community integration, **Objective 6.3**, accounted for 11% of the 2017 Question 6 funding with \$1.1 million and 15 projects. In 2018, this Objective was 24% of Question 6 funding (\$3.3 million) and included 19 projects. In 2017 and 2018, four projects in Question 6 were categorized as Core/Other. Projects assigned to Core/Other included studies of the cognitive and neural effects of aging in autism as well as an epidemiological study assessing adult outcomes. The **Cross-Cutting Objective** (CC1), which supports research to understand the sex differences of ASD, received 1% of the funding (1 project) in 2017 and 2018.

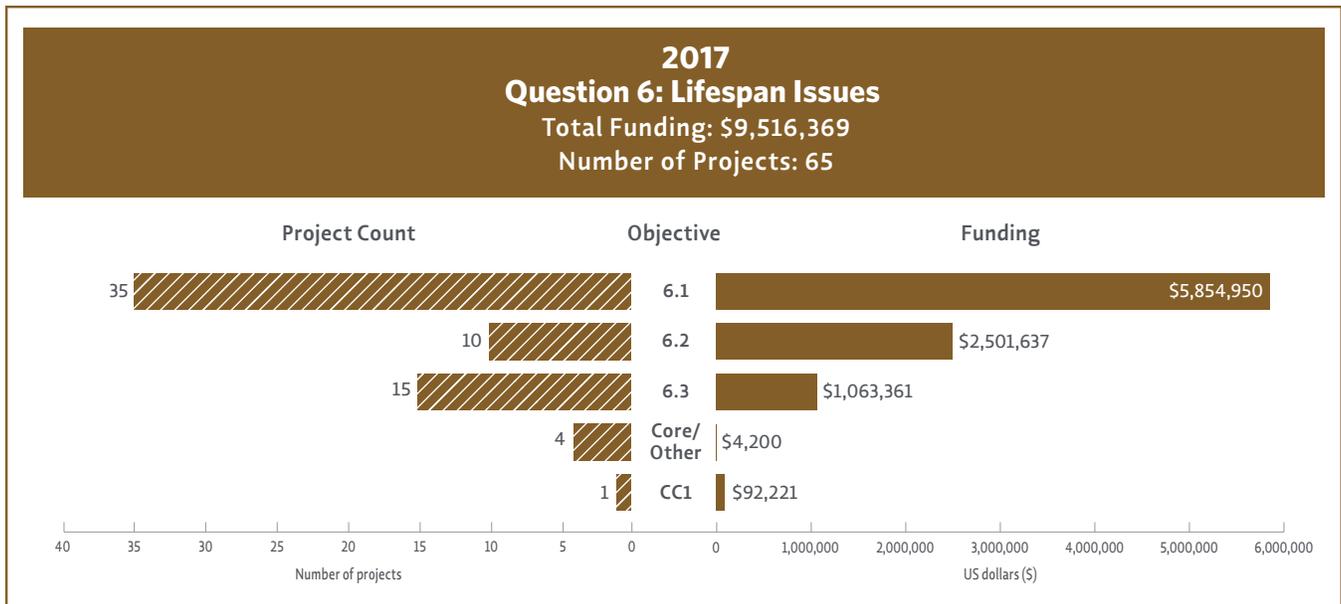


Figure 45. 2017 funding and project count by Question 6 Objectives. 6.1: Support development and coordination of integrated services to help youth make a successful transition to adulthood and provide supports throughout the lifespan; 6.2: Support research and implement approaches to reduce disabling co-occurring physical and mental health conditions in adults with ASD, 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; Core/Other: Projects that do not align with Question 6 Objectives or support "core" activities in the autism research field; CC1: Support research to understand the underlying biology of sex differences in ASD, possible factors that may be contributing to under diagnosis, unique challenges that may be faced by girls/women on the autism spectrum, and develop strategies for meeting the needs of this population.

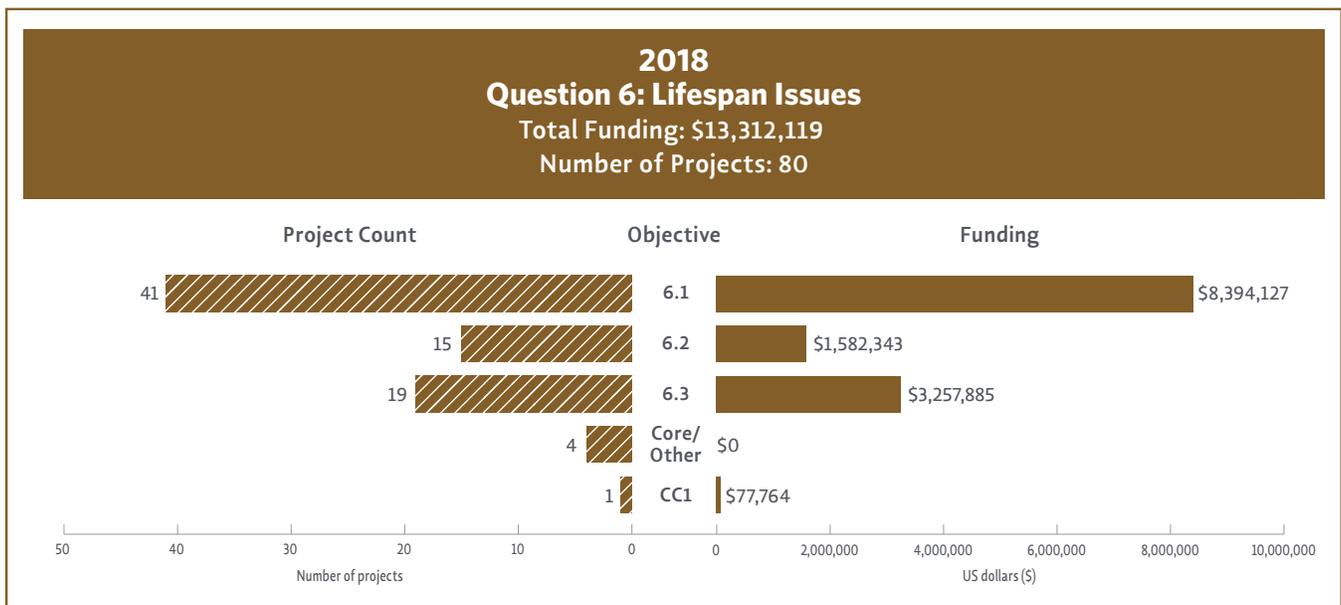


Figure 46. 2018 funding and project count by Question 6 Objectives. See Figure 45 caption above for descriptions of each Objective.

QUESTION 6 SUBCATEGORY ANALYSIS

From 2010-2016, the number of projects aligned with Question 6 were relatively low, limiting the opportunity to create subcategories within Question 6. Additionally, many projects in the Question 6 research area encompassed more than one topic, making it difficult to group these research projects into subcategories. However, in 2017 and 2018, there was a substantial increase in the number of projects aligned with Question 6, allowing projects for these years to be assessed for subcategory development. Based on the projects in the portfolio, in addition to priority areas discussed at IACC meetings, the OARC staff created five Question 6 subcategories that will be used to track trends in subtopics of research on ASD across the

lifespan: **Transition to adulthood and post-secondary outcomes, Community integration supports and services, Health and behavioral outcomes, Improving healthcare systems/Healthcare transitions, and Daily life skills (Figures 47 and 48)**. As mentioned previously, Question 6 projects typically address several subtopics within one project, sometimes making it difficult to assign to one subcategory. For the purposes of the *IACC Portfolio Analysis Report*, projects were only coded to one subcategory, aligning the project with its main research goal. Detailed descriptions of the new Question 6 subcategories are included in Appendix B.

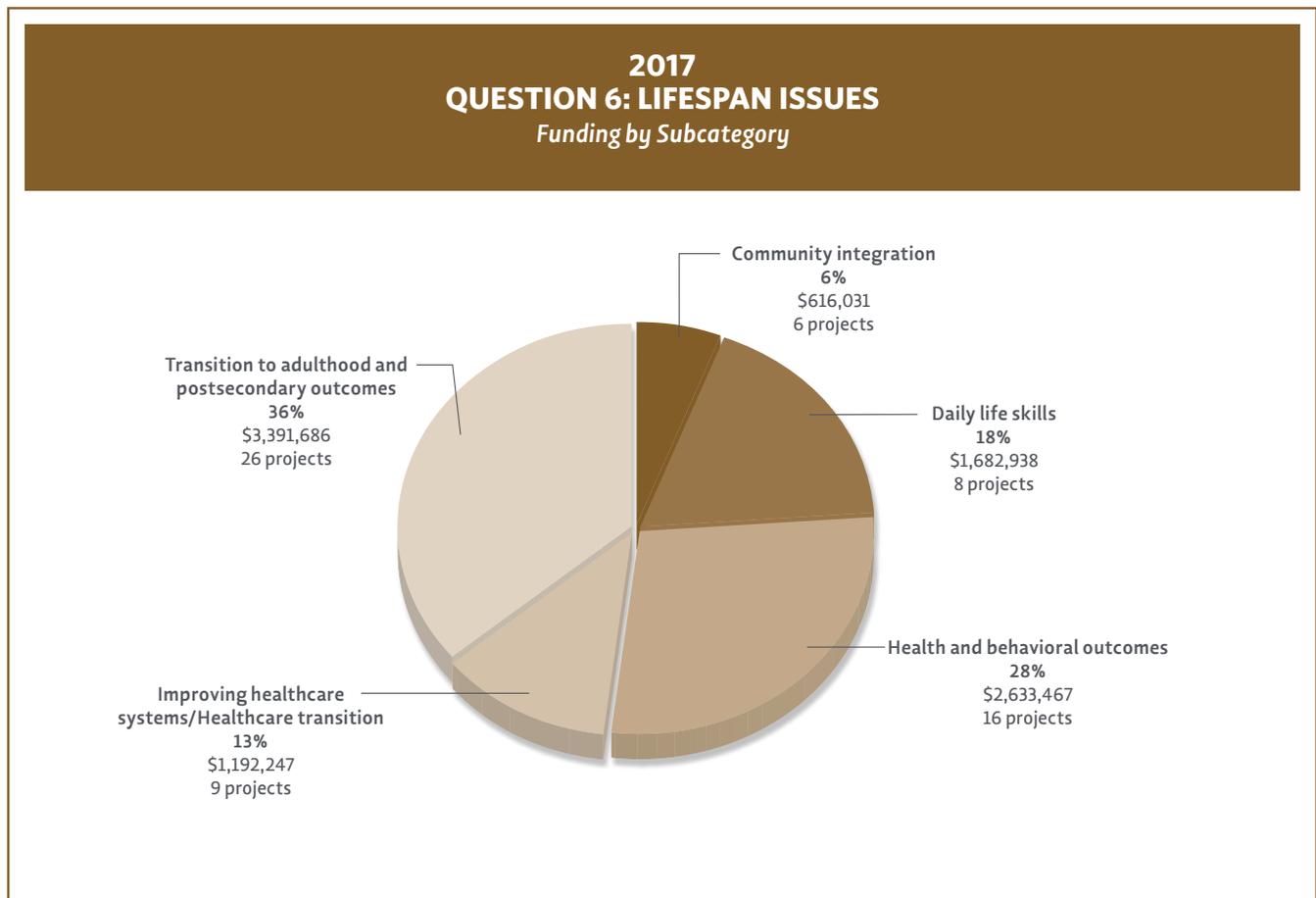


Figure 47. Question 6 funding by subcategory in 2017.

In 2017 and 2018, the largest funded subcategory was **Transition to adulthood and post-secondary 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 2017, this subcategory received 36% of Question 6 funding and included 26 projects. In 2018, this subcategory received 39% of funding and totaled 31 projects. **Health and behavioral outcomes** focus on understanding the health-related outcomes for youth and adults, including interventions for co-occurring conditions and core disabilities; this subcategory accounted for 28% of Question 6 funding in 2017 (16 projects) and 14% of funding in 2018 (14 projects). **Daily life skills** include projects that teach independent living skills, such as self-determination and goal setting, to youth and adults. In 2017 and 2018,

daily life skills accounted for 18% of Question 6 funding (8 projects in 2017 and 15 projects in 2018). **Improving healthcare systems/Healthcare transitions** includes projects focused on improving provider-patient experiences and the development of specific screening and diagnostic tools for ASD in adults and co-occurring conditions related to ASD. In 2017, this subcategory had 13% of Question 6 funding and included nine projects; in 2018, it aligned with 14% of funding and had 11 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 ASD. This subcategory received 6% of funding in 2017 (6 projects) and 15% of funding in 2018 (9 projects).

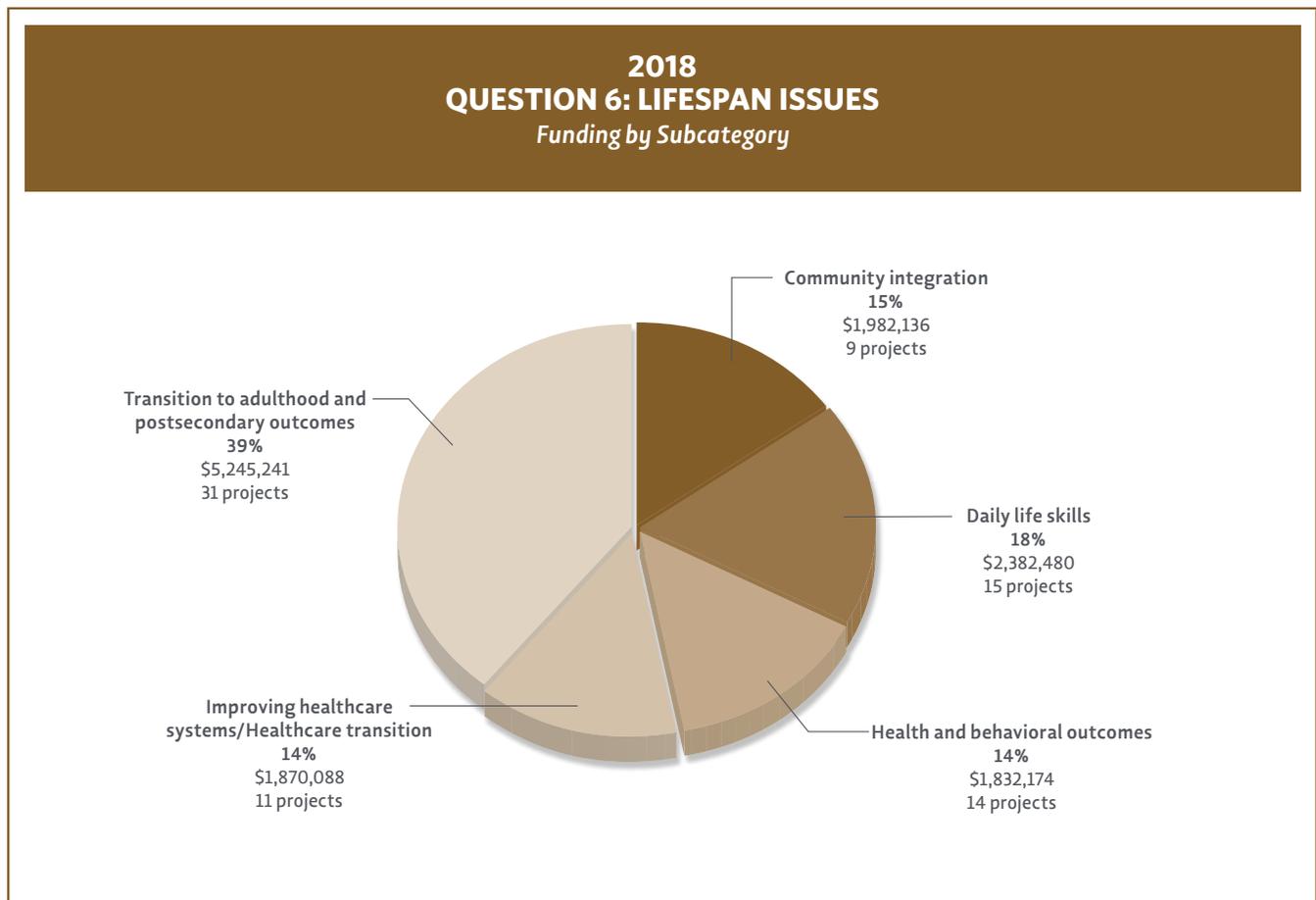


Figure 48. Question 6 funding by subcategory in 2018.

FUNDING PROGRESS MADE ON QUESTION 6 FROM 2008-2018

Research related to Question 6 has received the lowest level of annual funding for every year of the eleven-year analysis period (**Figure 49**). Although there was a small increase in funding for this Question area from 2009-2010 and 2014-2018, the overall trend shows that funding for this Question has stayed low and relatively flat. However, Question 6 experienced its highest amount of funding in 2018.

In the 2016-2017 IACC Strategic Plan, the IACC recommended a doubling of ASD research funding, including increased funding for research on adults, to better understand autism in adulthood and to develop tools, strategies, and best practices for addressing the needs of autistic adults. This area will continue to be monitored for progress toward that recommendation in the future.

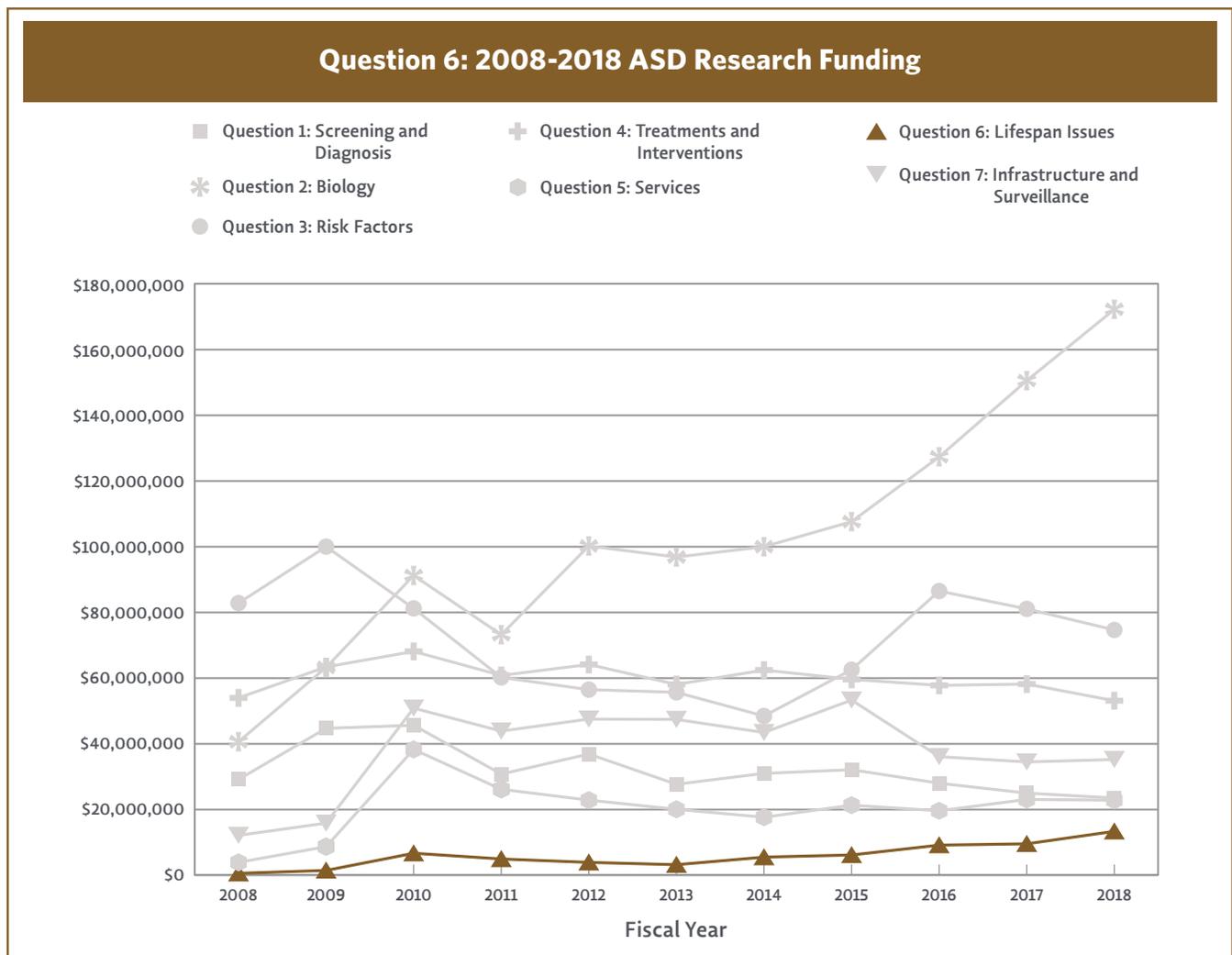


Figure 49. Question 6 ASD research funding from 2008-2018. Funding for Question 6 remained low over the eleven-year span but recently experienced a slight increase.

ANALYSIS OF 2017-2018 QUESTION 7 PORTFOLIO

Projects assigned to Question 7 comprised 9% (\$34.5 million) of the total ASD research supported in 2017 and consisted of 139 projects, which was 9% of the total number of projects. In 2018, Question 7 accounted for 9% of the total research funding (\$35.2 million) and 9% of total projects (142 projects). In 2017 and 2018, the National Institutes of Health, Simons Foundation, and the Centers for Disease Control and Prevention were the largest funders of Question 7 research. Question 7 consists of four primary Objectives and the Cross-Cutting Objective. **Figures 50** and **51** provide a detailed overview of each Objective's total funding as well as the number of projects assigned to each Objective.

Question 7's primary four Objectives received funding in 2017 and 2018. In 2017, the largest portion of funding went towards **Objective 7.2**, which focuses on developing and enhancing data banks and data sharing (\$12.2 million, 35% of funding). Objective 7.2 had 23 projects; this is not the largest share of projects in Question 7, as projects focused on data infrastructure often require more funding per project. In 2018, Objective 7.2 accounted for 33% of Question 7 funding (\$11.5 million) and had 18 projects. Funding towards programs enhancing the research workforce and developing interdisciplinary training (**Objective 7.3**) received the second largest amount of funding

(\$7.4 million, 22%) in 2017 and had greatest portion of projects (58 projects). Objective 7.3 also had the largest number of projects (66 projects) in 2018, with \$8.5 million (24%) in funding. **Objective 7.4** followed with \$6.3 million (18%) in 2017 and 18 projects; this Objective supports the expansion of ASD surveillance systems. In 2018, this Objective accounted for \$5.7 million (16%) and had 17 projects. **Objective 7.1**, which supports increasing biospecimen donations and encouraging integration of biorepository banks, was 13% of Question 7 funding (\$4.3 million) in 2017 and had 14 projects; in 2018, Objective 7.1 accounted for \$4.1 million (12%) and had 12 projects. In 2017, there were 26 projects, accounting for \$4.2 million, that did not fit into a specific Question 7 Objective and were assigned to Core/Other. Comparably, there were 29 projects with \$5.3 million in funding towards Core/Other in 2018. Projects assigned to Core/Other include data and administrative centers for large, multisite research projects and a project supporting the development of a research agenda for online STEM K-12 education. The **Cross-Cutting Objective** (CC1) did not receive any funding under Question 7 in 2017 or 2018. Research within the Cross-Cutting Objective that would be relevant to Question 7 would include infrastructure, surveillance, researcher training, or dissemination of findings related to research on sex differences in ASD.

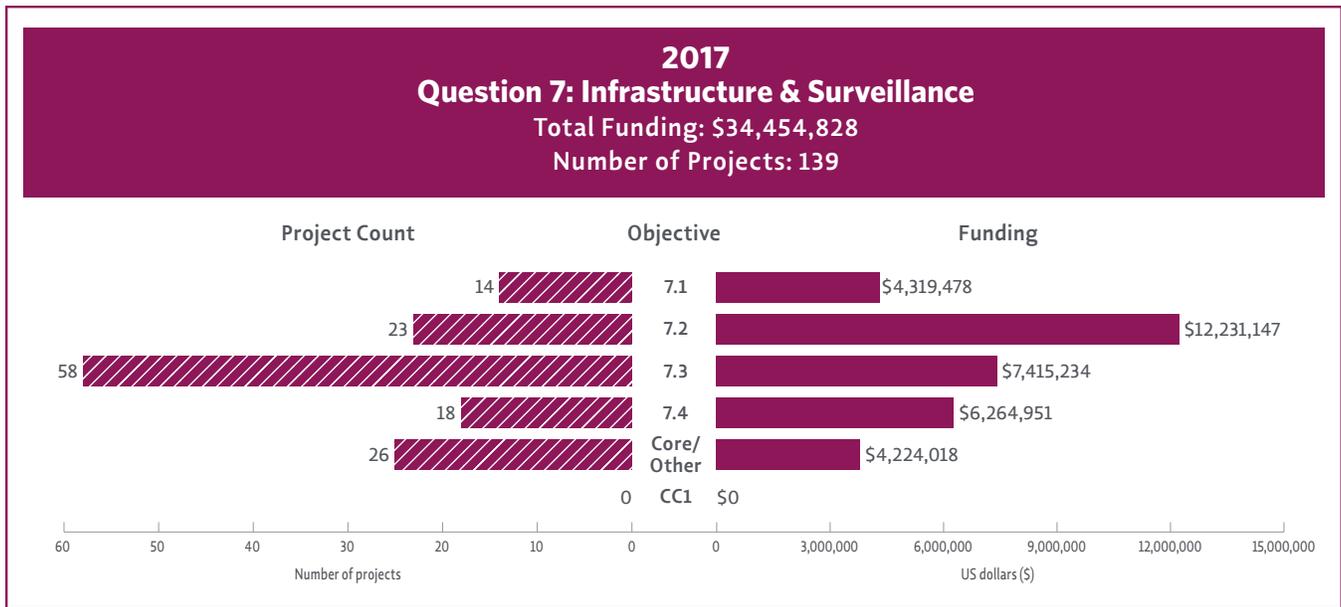


Figure 50. 2017 funding and project count by Question 7 Objectives. 7.1: Promote growth, integration, and coordination of biorepository infrastructure; 7.2: Develop, enhance, and link data repositories; 7.3: Expand and enhance the research and services workforce, and accelerate the pipeline from research to practice; 7.4: Strengthen ASD surveillance systems to further understanding of the population of individuals with ASD, while allowing comparisons and linkages across systems as much as possible; Core/Other: Projects that do not align with Question 7 Objectives or support "core" activities in the autism research field; CC1: Support research to understand the underlying biology of sex differences in ASD, possible factors that may be contributing to under diagnosis, unique challenges that may be faced by girls/women on the autism spectrum, and develop strategies for meeting the needs of this population.

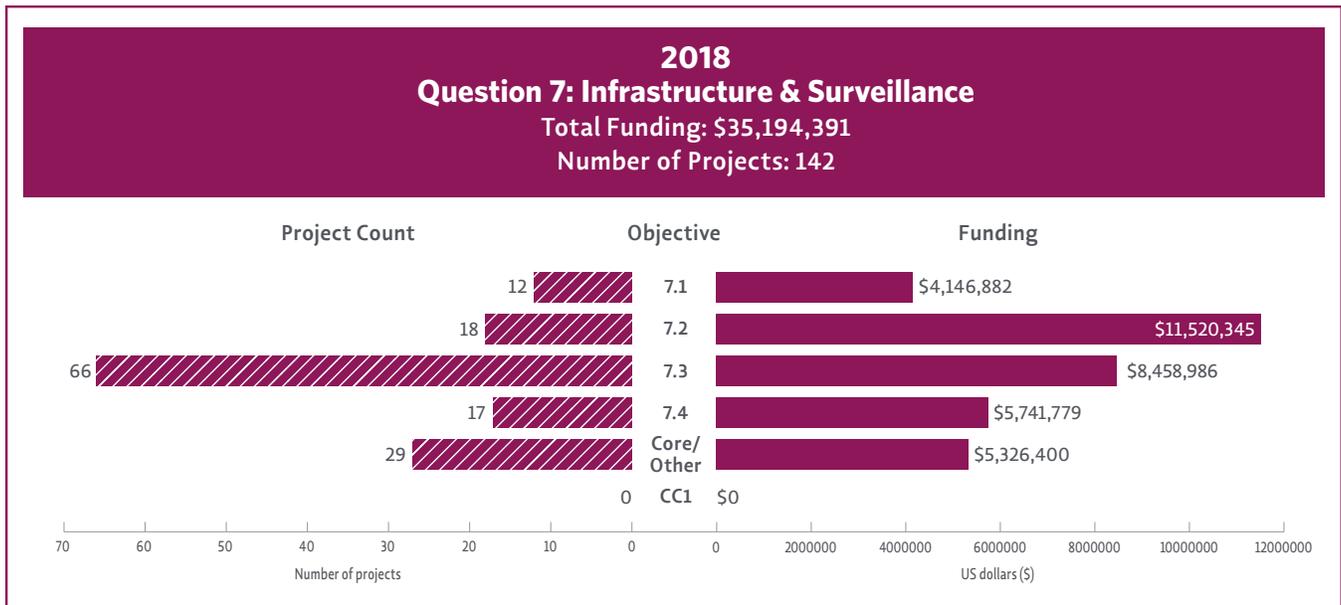


Figure 51. 2018 funding and project count by Question 7 Objectives. See Figure 50 caption above for descriptions of each Objective.

QUESTION 7 SUBCATEGORY ANALYSIS

The six subcategories in Question 7 reflect the broad array of ASD research infrastructure needs that have been identified by the IACC: **Biobanks; Data tools; Research infrastructure; Research recruitment and clinical care; Research workforce development;** and **Surveillance and prevalence studies** (Figures 52 and 53).

In Question 7, the subcategories encompass a diverse set of project types, with funding distributed relatively evenly across them. In 2017 and 2018, **Data tools**,

such as the National Database for Autism Research (NDAR) and the Autism Genetics Resource Exchange (AGRE), received the largest portion of funding (2017: 34%, 19 projects; 2018: 35%, 19 projects).

Surveillance and prevalence studies, such as studies under the ADDM Network, had 18% of Question 7 funding (18 projects) in 2017 and 16% of funding (18 projects) in 2018. **Research workforce development**, which supports conferences and training for autism researchers, accounted for 14% of funding in 2017 (38

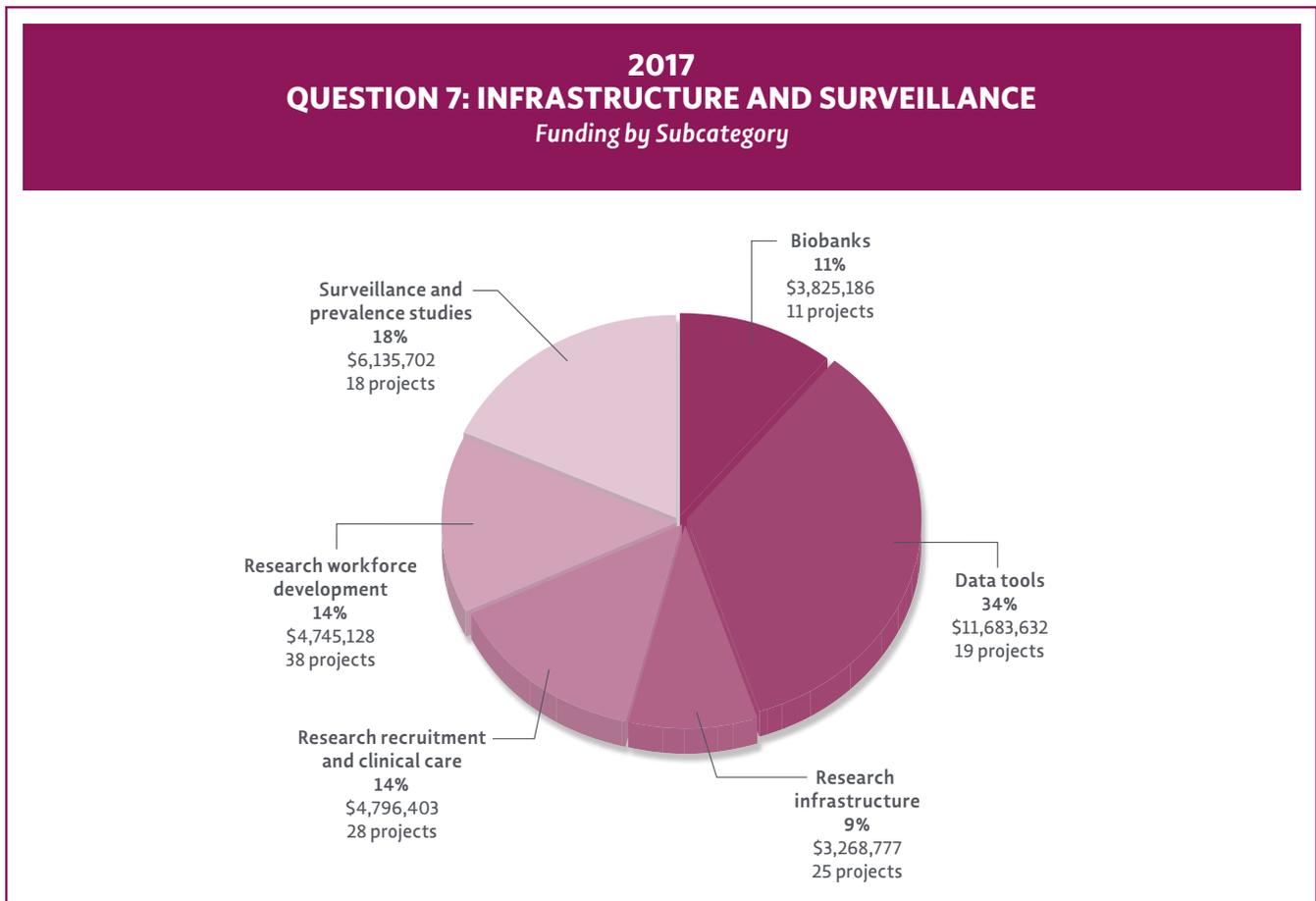


Figure 52. Question 7 funding by subcategory in 2017.

projects) and 16% in 2018 (44 projects). **Research recruitment and clinical care**, which helps increase participation in research studies and conduct medical evaluations of participants, received 14% of funding (28 projects) in 2017; this subcategory received 10% of Question 7 funding in 2018 (32 projects). **Biobanks** received 11% of Question 7 funding in 2017 (11 projects) and 10% of funding in 2018 (6 projects). Funding supporting coordinating centers that analyze data and disseminate research to the community are included

within **Research infrastructure**, which received 9% of Question 7 funding in 2017 (25 projects) and 13% of 2018 funding (23 projects). The increase in 2018 funding for Research infrastructure included the addition of two new large projects; the first funded by the New Jersey Governor’s Council for Medical Research and Treatment of Autism to establish the **New Jersey Autism Center of Excellence** and the second funded by the National Institutes of Health to support the **Duke Center for Autism and Brain Development**.

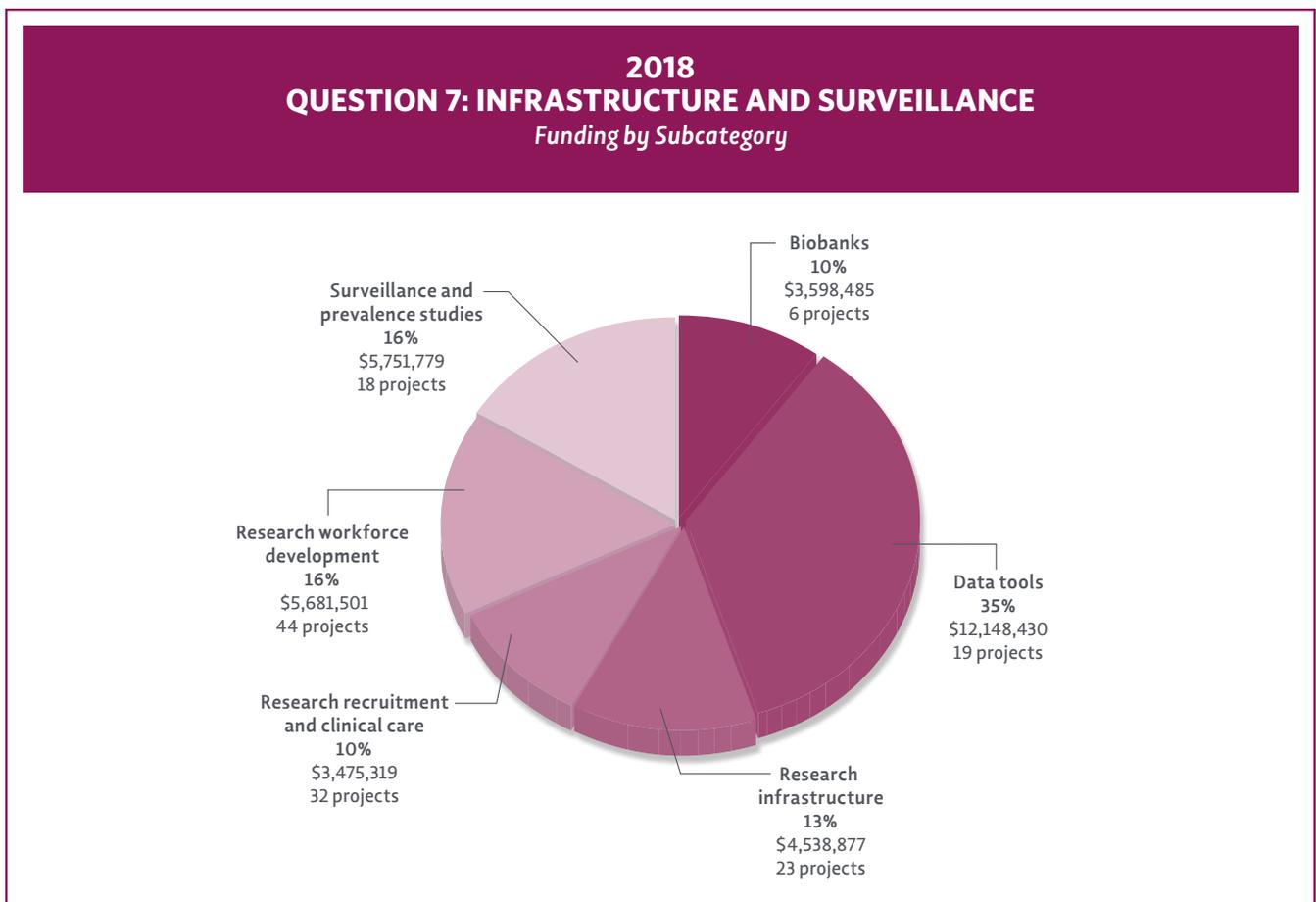


Figure 53. Question 7 funding by subcategory in 2018.

FUNDING PROGRESS MADE ON QUESTION 7 FROM 2008-2018

Figure 54 shows the trend in Question 7 funding over the eleven-year span of 2008-2018. Research within Question 7 experienced a rapid increase in funding from 2008-2010. After 2010, funding levels for infrastructure and surveillance projects leveled off to

a flat, moderate level from 2010-2014. The year 2015 saw a slight increase in funding for Question 7 research projects; however, it was followed by a significant decrease in 2016. Funding levels have since remained relatively stable in 2017 and 2018.

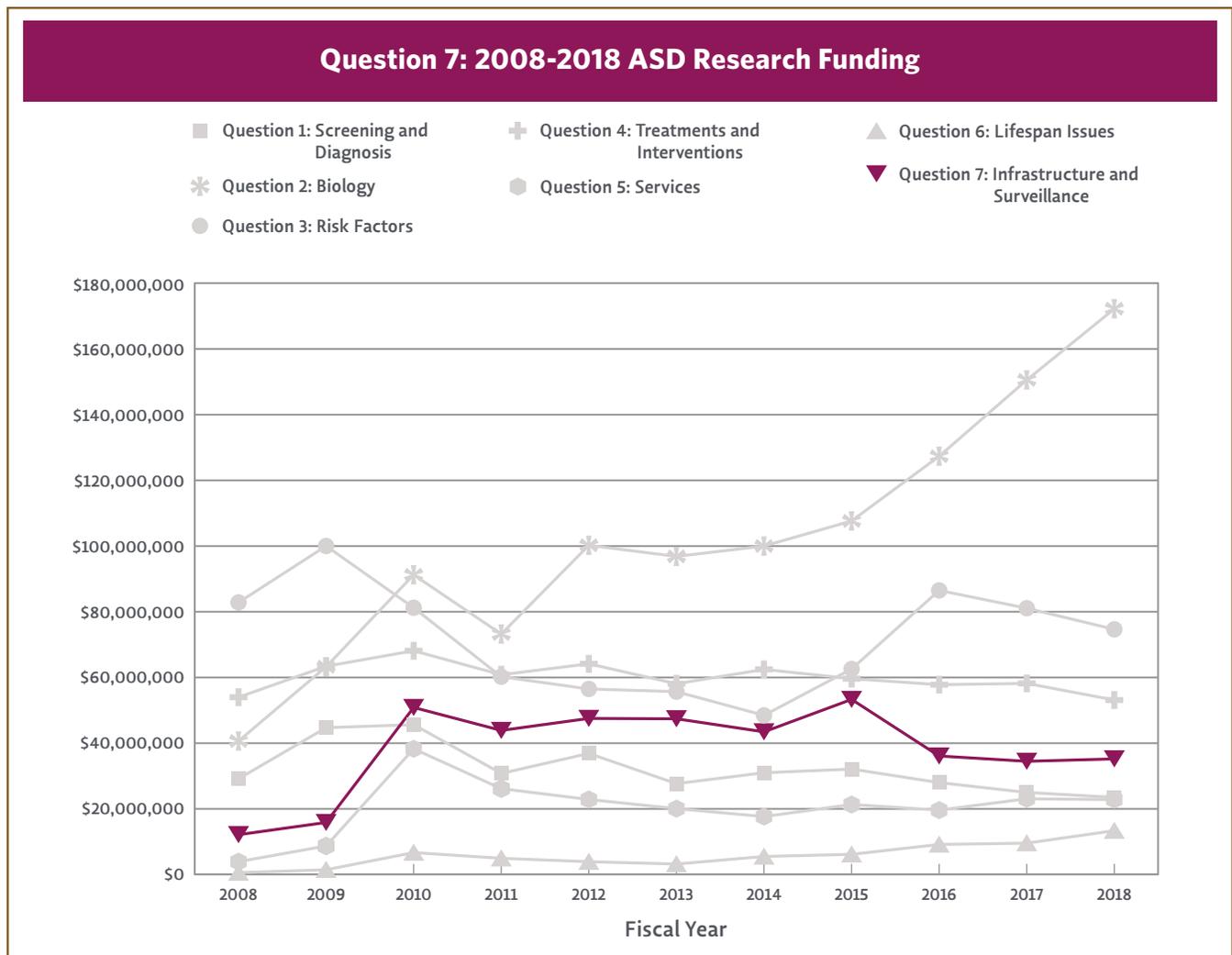


Figure 54. Question 7 ASD research funding from 2008-2018. Following an initial increase from 2008-2010, funding for Question 7 remained relatively flat from 2010-2018.

Cross-Cutting Objective: Sex Differences in ASD

In addition to the 22 primary Objectives, the 2016-2017 IACC *Strategic Plan* includes one **Cross-Cutting Objective (CC1)** on the topic of ASD in females: “Support research to understand the underlying biology of sex differences in ASD, 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.” This “Cross-Cutting” Objective was developed to combine the priorities on research and services to understand and better serve the needs of girls and women on the autism spectrum. Individual projects assigned to this Objective are coded to different Questions of the *Strategic Plan* depending on which aspect of ASD 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 added together into a single Objective. The goal of a single “Cross-Cutting” Objective on girls and women with ASD is to encompass the numerous research and services priorities identified by the Committee throughout the *Strategic Plan* and allow for this area to be identified as a priority for funders. Examples of projects that are included in the Cross-Cutting Objective are those that focus on the underlying biology of ASD in girls/women (differences in brain structure, function, physiology), development of strategies to meet the intervention,

service, and support needs of girls/women with ASD, identifying factors that contribute to sex differences, and projects that develop, adapt, or validate screening and diagnostic tools to detect ASD in girls and women.

The Question-specific sections above provide an illustration of projects and funding devoted to the Cross-Cutting Objective within each Question area of the *Strategic Plan*. In this section, we provide additional analysis of the Cross-Cutting Objective across all Questions to provide a complete depiction of the number of projects and funding that were dedicated to the topic of ASD in girls/women. In 2017, the amount of funding devoted to the Cross-Cutting Objective totaled \$7.5 million (2% of total funding) and spanned 33 projects (**Figure 55**). Question 2 (Biology) accounted for the bulk of projects that fell under the Cross-Cutting Objective, receiving over \$6 million in research funding for 25 projects (85% of total funding for the Cross-Cutting Objective). Question 3 (Risk Factors) accounted for 11% of funding (\$860,135, 5 projects). Question 4 (Treatments and Interventions) accounted for 2% of funding (\$180,000, 2 projects), and one project under Question 6 (Lifespan Issues) received \$92,221 (1% of funding). Questions 1 (Screening and Diagnosis), 5 (Services), and 7 (Infrastructure and Surveillance) did not have any projects in 2017 that were included in the Cross-Cutting Objective.

In 2018, the amount of funding aligned with the Cross-Cutting Objective totaled \$5.5 million (1.4% of total funding) and spanned 35 projects (**Figure 56**). Question 2 (Biology) again accounted for the majority of projects that fell under the Cross-Cutting Objective, receiving \$4.4 million in research funding for 28 projects (80% of total funding for the Cross-Cutting Objective). Question 3 (Risk Factors) accounted for 18% of funding (\$1 million, 4 projects). Question 6 (Lifespan Issues) accounted for 1% of funding (\$77,764, 1 project), Question 1 (Screening and Diagnosis) received less than 1% of the Cross-Cutting Objective funding with one

project included at \$25,000. Question 4 (Treatments and Interventions) maintained one ongoing project which did not receive funding. Question 5 (Services) and Question 7 (Infrastructure and Surveillance) did not have any projects in 2018 that were included in the Cross-Cutting Objective. Those Question research areas with little to no funding in the Cross-Cutting Objective identify areas where future research can fill in gaps. The IACC will continue to track the funding progress of the Cross-Cutting Objective as it relates to the broader autism research landscape.

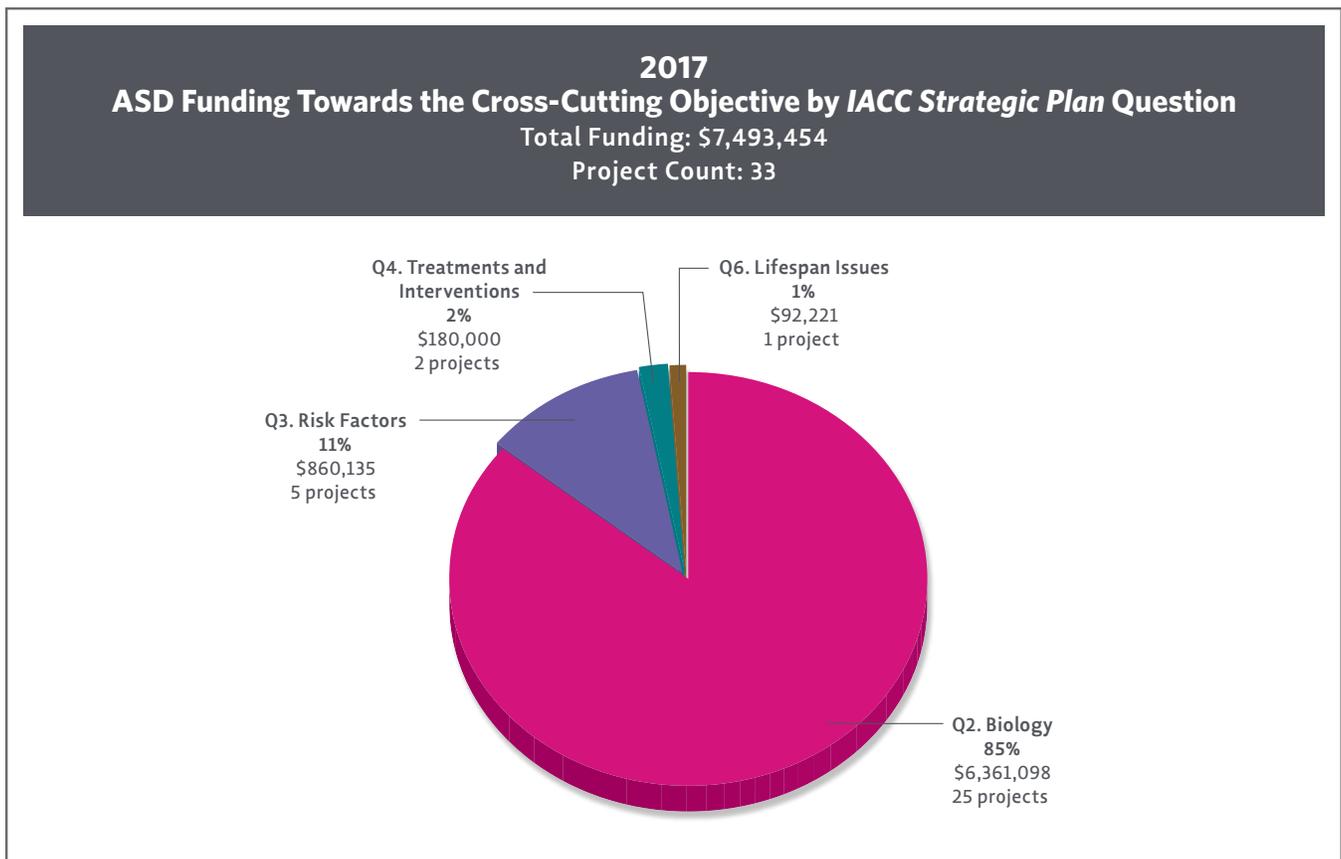


Figure 55. 2017 ASD research funding dedicated to the Cross-Cutting Objective by IACC Strategic Plan Question.

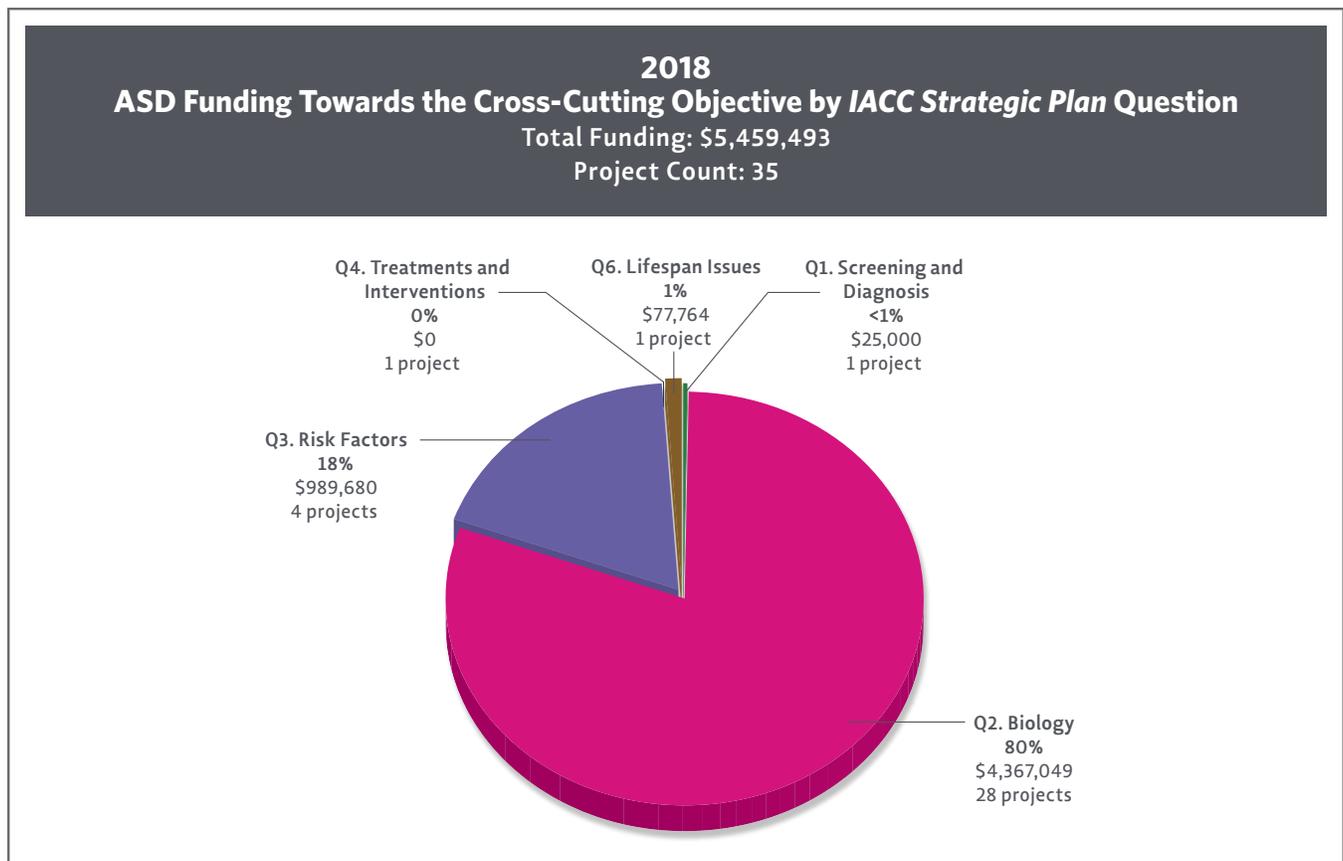


Figure 56. 2018 ASD research funding dedicated to the Cross-Cutting Objective by IACC Strategic Plan Question.

Cross-Cutting Theme: Racial/Ethnic Disparities in ASD

Research demonstrates ongoing significant racial, ethnic, socioeconomic, and geographic disparities that are experienced by people with ASD. These are evident in areas such as rates and age of diagnosis, access to and utilization of services, and implementation and availability of culturally-sensitive 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 2017-2018 IACC ASD research portfolio was conducted.* This is the first time that such an analysis has been undertaken in an *IACC Portfolio Analysis Report*.

This analysis provides an overview of the proportion of ASD research funding that was allocated to projects that address racial, ethnic, socioeconomic, and geographic disparities within the ASD population. These projects focused on 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, ASD, and early life exposure to traffic density and residential proximity to major roadways, and modification of existing ASD 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 under-represented minority groups to expand the diversity of the ASD scientific workforce.

In 2017, \$21.3 million in research funding was dedicated to projects addressing racial, ethnic, socioeconomic, and geographic disparities within the ASD population (see **Figure 57**). This represents 6% of total ASD research funding in 2017 (81 projects). Additional analyses were conducted to determine the proportion of research funding on disparities within each *Strategic Plan* Question area (**Figure 58**). All seven Questions included projects of this kind. Question 1 (Screening and Diagnosis) had the largest proportion of its funding directed toward projects that addressed disparities within the ASD population (33%, \$8.3 million, 19 projects). This was followed by Question 5 (Services), to which 21% of funding was dedicated to projects that fell under this theme (\$4.8 million, 28 projects). Question 3 (Risk Factors) had 5% (\$4.3 million, 8 projects) of funding dedicated to projects on this theme, while 3% (\$1.7 million, 9 projects) of Question 4 (Treatments and Interventions) funding and 4% (\$1.2 million, 9 projects) of Question 7 (Infrastructure and Surveillance) funding aligned with research on disparities. Lastly, 1% of funding (\$889,351, 3 projects) for Question 2 (Biology) and 0.3% of funding (\$30,000, 5 projects) for Question 6 (Lifespan issues) went to projects on the topic of disparities in ASD. **Figure 59** illustrates the proportion of ASD disparities funding that was dedicated to each Question area. Of the total \$21.3 million that was dedicated to projects addressing disparities within the ASD population in 2017, Question 1 (Screening and Diagnosis) was the category that received the largest proportion of funding (39%). This was followed by Question 5 (Services, 23%) and Question 3 (Risk Factors, 20%).

* Some (but not all) of these projects fell under the following relevant *Strategic Plan* Objectives: 1.2. Reduce disparities in early detection and access to services; 5.2. Reduce disparities in access and in outcomes for underserved populations.

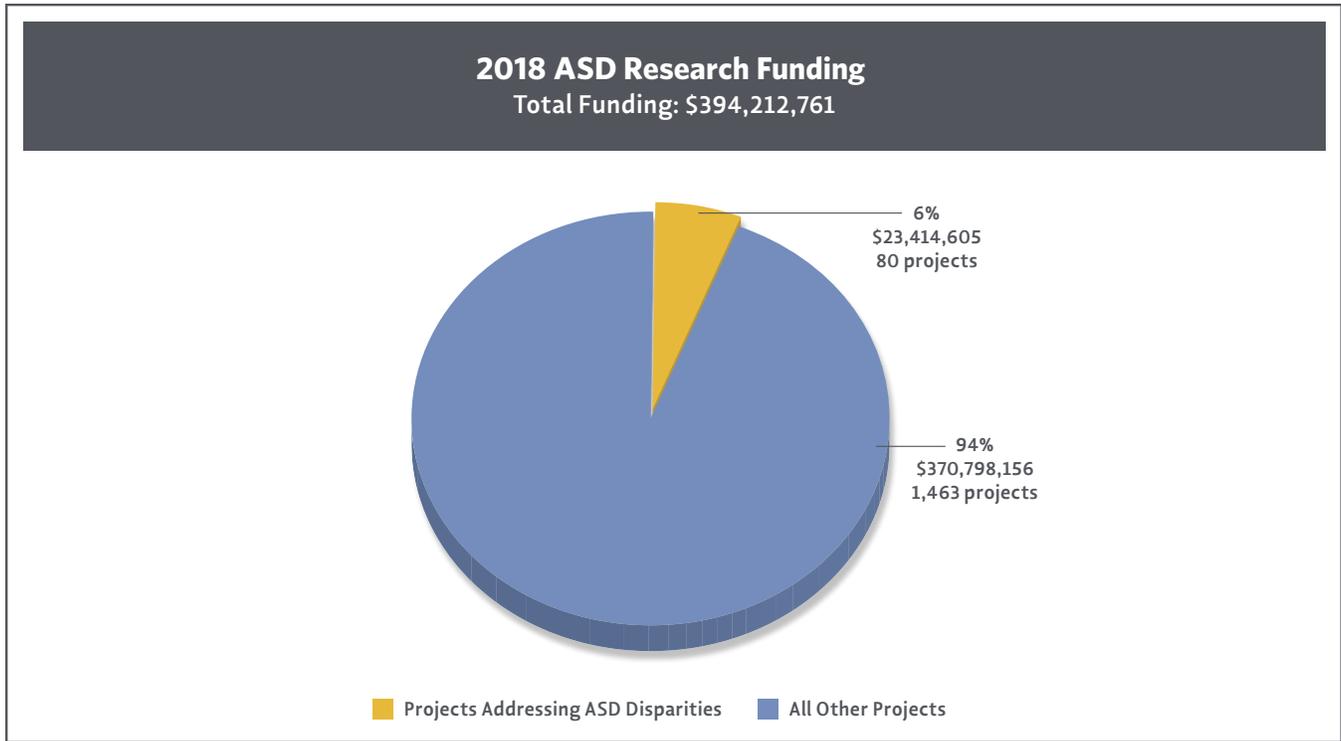


Figure 57. 2018 ASD research funding dedicated to addressing disparities in ASD. In 2017, the proportion of projects dedicated to addressing ASD disparities was the same as in 2018 (6%), with similar funding (\$21,347,616) and number of projects (81 projects).

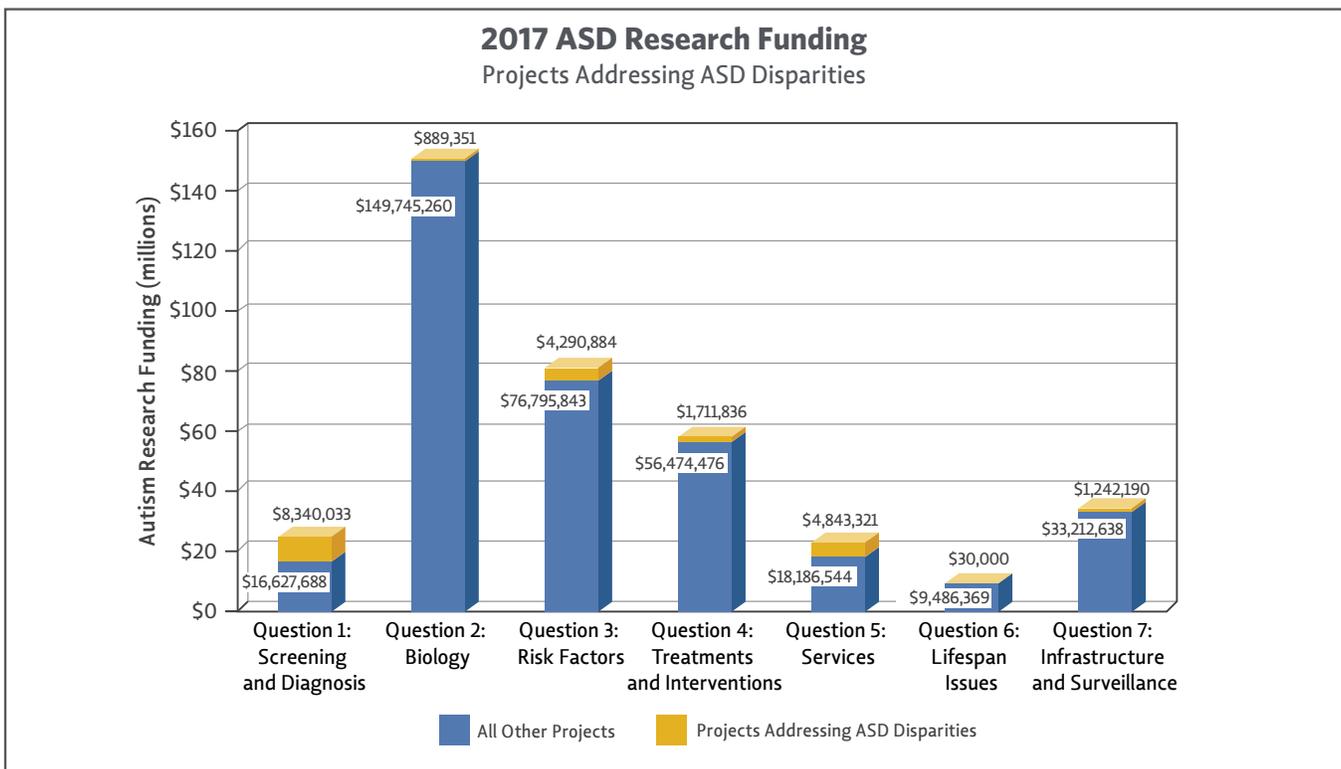


Figure 58. Projects addressing racial, ethnic, socioeconomic, and geographic disparities within the ASD population were included in each *Strategic Plan* Question area in 2017. The proportion of funding dedicated to this topic varied between Question areas; Question 1 (Screening and Diagnosis) had the largest proportion, and Question 6 (Lifespan Issues) had the smallest proportion of projects focused on disparities in ASD.

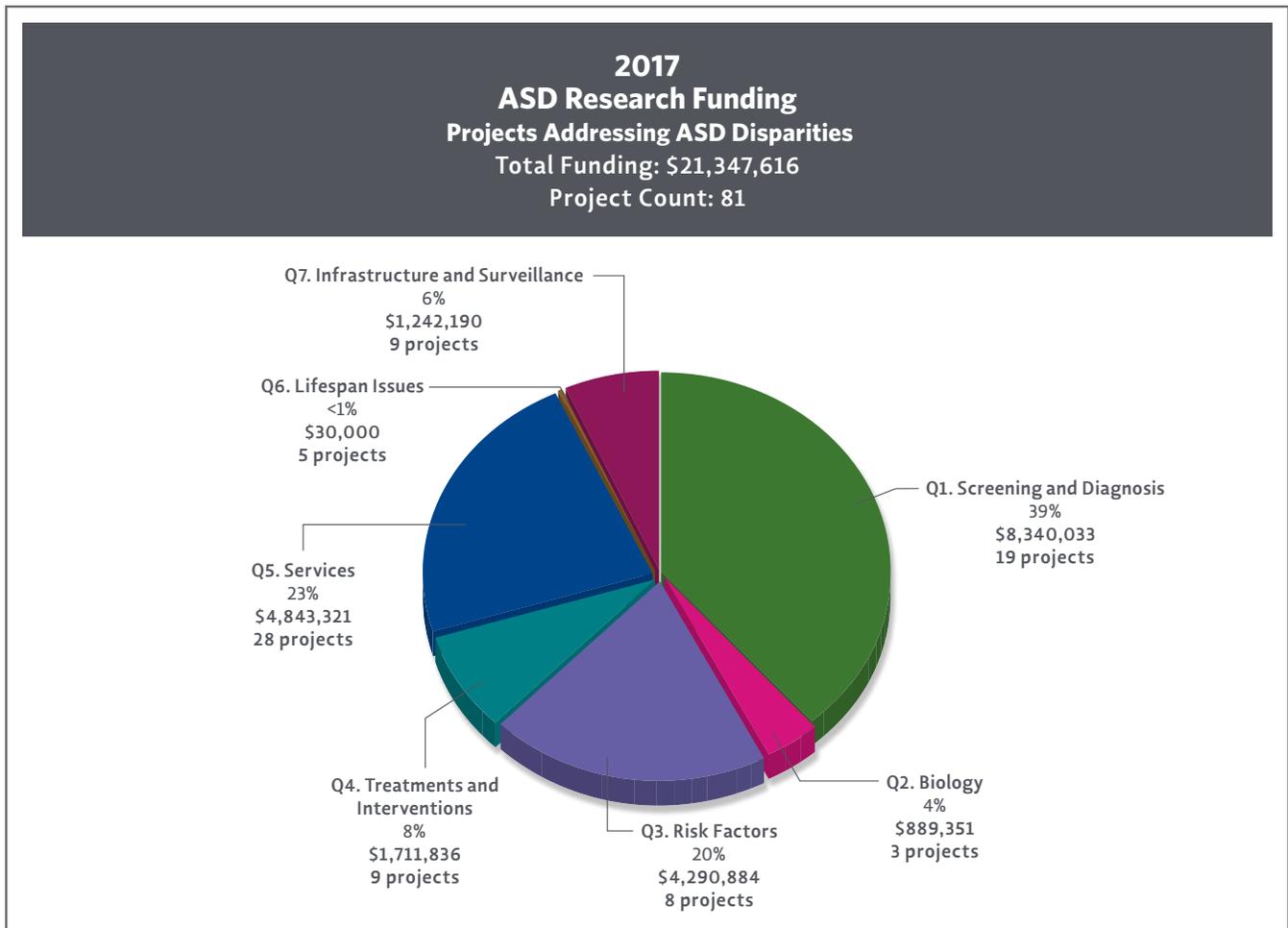


Figure 59. 2017 ASD research funding dedicated to addressing disparities in ASD by IACC Strategic Plan Question.

In 2018, \$23.4 million of ASD research funding prioritized racial, ethnic, socioeconomic, and geographic disparities, which represented 6% of total funding (**Figure 57**). All seven Questions of the IACC Strategic Plan included research on this topic. Similar to 2017, Question 1 (Screening and Diagnosis) had the largest portion of its funding dedicated to addressing disparities research (40%, \$9.4 million, 24 projects) (**Figure 60**). Question 5 (Services) followed with 26% of funding emphasizing research on these areas (\$6 million, 26 projects), and Question 3 (Risk Factors) included 6% of funding devoted to disparities research (\$4.8 million, 6 projects). Question 7 (Infrastructure and Surveillance) had 4% of funding supporting

research on this topic (\$1.4 million, 8 projects).

Question 4 (Treatments and Interventions) included 1% of funding (\$765,551, 8 projects), and 2% of Question 6 (Lifespan Issues) funding focused on disparities in the ASD population (\$199,999, 5 projects). Less than 1% of Question 2's (Biology) funding aligned with disparities research (\$838,882, 3 projects). In 2018, the proportion of ASD disparities funding for each Question area (**Figure 61**) remained relatively consistent with those observed for 2017. Of the total \$23.4 million in 2018, Question 1 (Screening and Diagnosis) was the category that received the largest proportion of funding (40%). This was followed by Question 5 (Services, 26%) and Question 3 (Risk Factors, 21%).

This indicates that research related to disparities has been most concentrated in studies on early detection, services access and delivery, and genetic and environmental factors. It is notable that only a small proportion of projects in the highest-funded area of ASD research overall, Question 2 (Biology), were

focused on understanding disparities. This is a critically important area, and the *IACC Portfolio Analysis Report* will continue to track progress and research funding for projects that address racial, ethnic, socioeconomic, and geographic disparities in the ASD population.

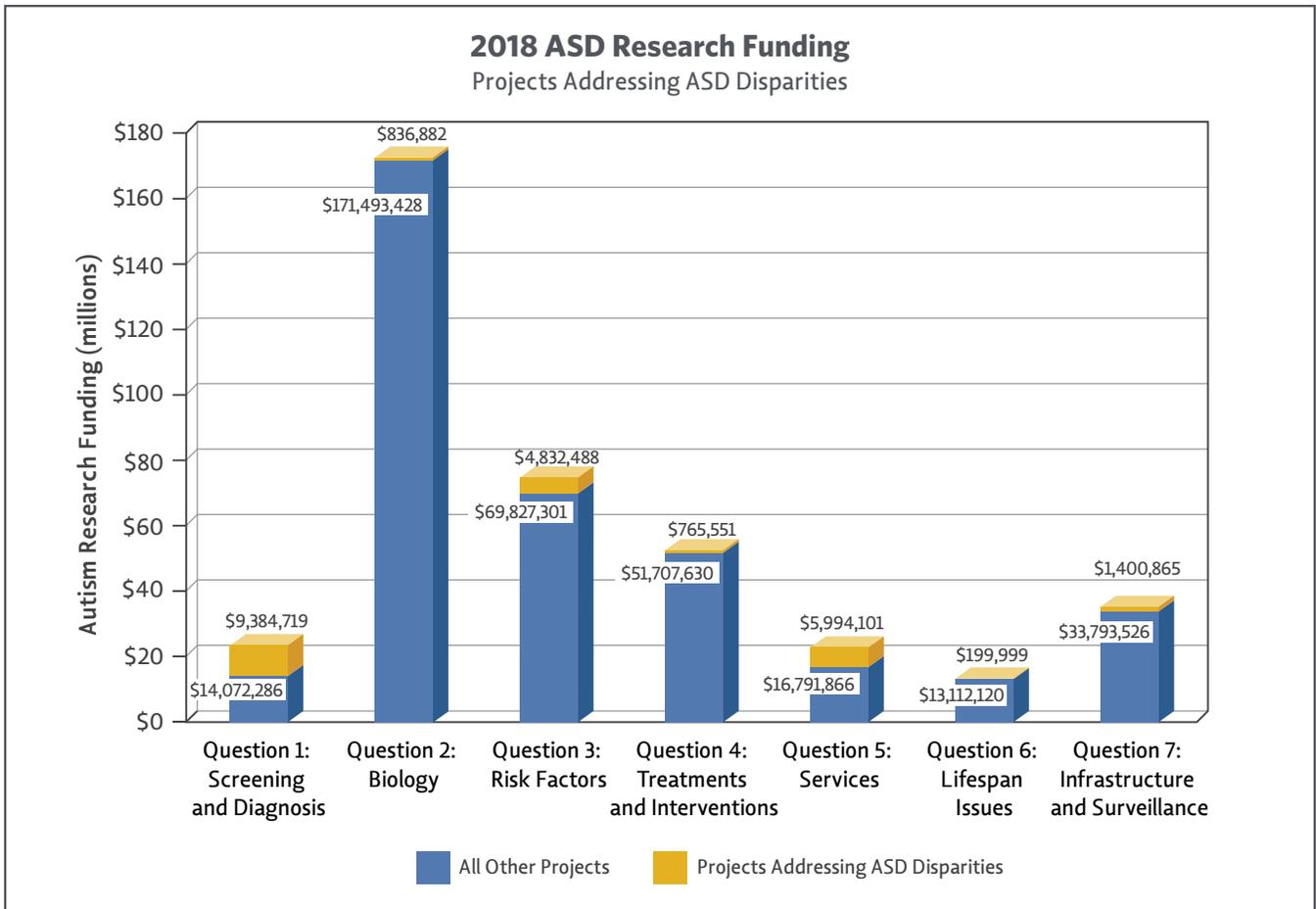


Figure 60. Projects addressing disparities within the ASD population were included in each *Strategic Plan* Question area in 2018. Similar to 2017, Question 1 funding had the largest proportion of funding dedicated to research on disparities in ASD, and Question 6 had the smallest proportion of funding.

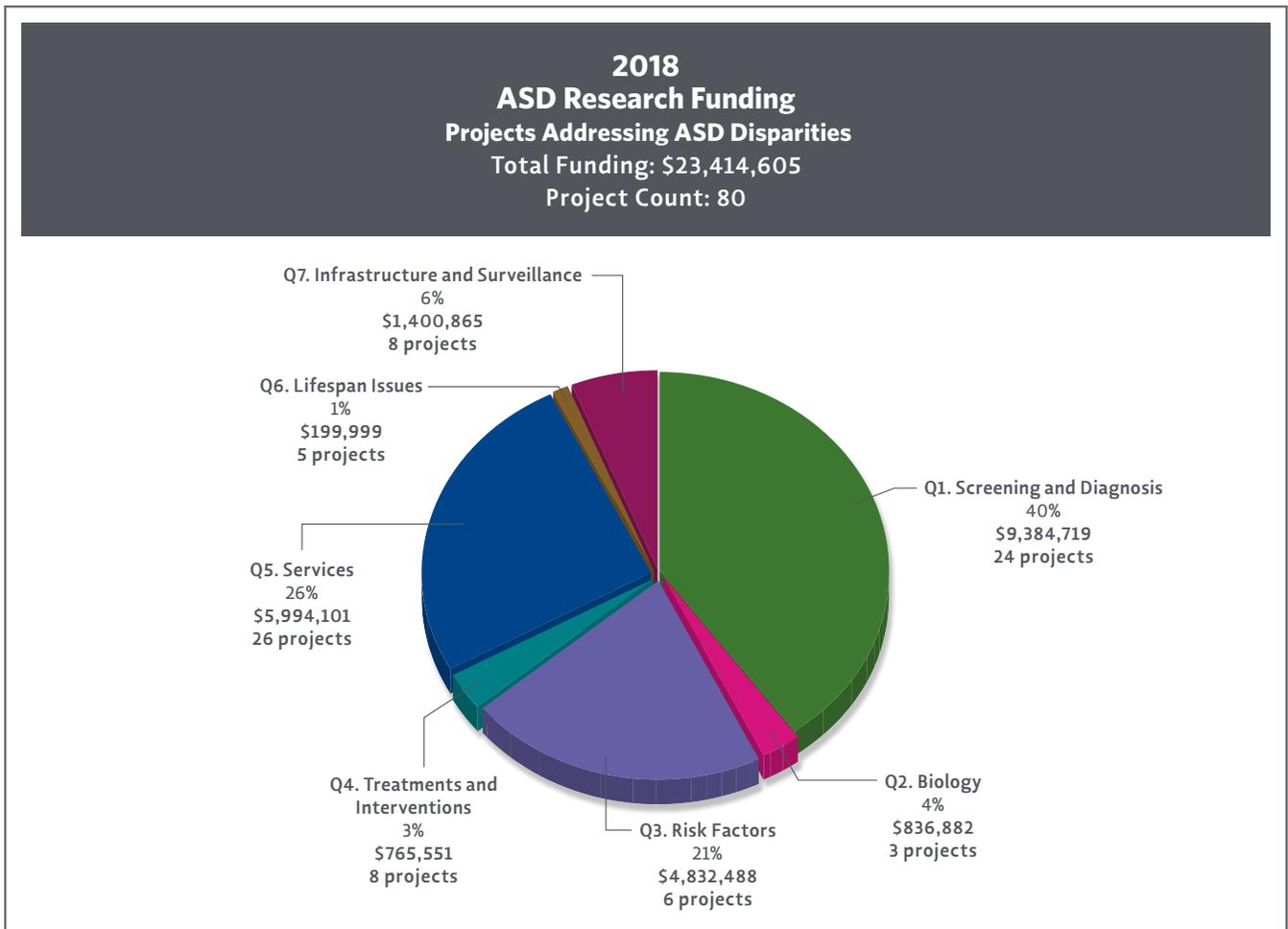


Figure 61. 2018 ASD research funding dedicated to addressing disparities in ASD by IACC Strategic Plan Question.

Summary and Conclusion

The *2017-2018 IACC ASD Research Portfolio Analysis Report* represents the tenth and eleventh years of data collected and the eighth comprehensive report of U.S. ASD research funding across both the federal and private sectors. It is the second analysis to measure research funding progress against the 23 Objectives from the *2016-2017 IACC Strategic Plan*. Project information was collected from 23 federal and private funders; the diverse missions of the different funders are reflected in the ASD research portfolio across the seven Questions of the *Strategic Plan*. Comparable to previous years, federal agencies funded approximately 80% of ASD research while private organizations contributed approximately 20% of funding. Among the participating funders, the National Institutes of Health continued to contribute the largest amount of federal funding toward autism research, and the Simons Foundation was the largest private funder.

Overall, funding for ASD research among both federal and private funders totaled \$381.9 million and spanned 1,508 projects in 2017 and totaled \$394.2 million and spanned 1,543 projects in 2018. In 2017 and 2018, five new funders contributed to the portfolio analysis, providing an updated and more comprehensive view of the ASD research funding landscape. With eleven years of ASD research funding data available, it was possible to continue analyzing funding trends, enabling meaningful observations about the long-term progress in ASD research funding over the period from 2008-2018. Over these eleven years, autism research showed an overall upward trend in funding, increasing by 77.4% since 2008. New funders added breadth to the portfolio but did not have a large impact on overall funding trends.

One of the key aims of the *Portfolio Analysis Report* is to evaluate the progress made in addressing the research priorities as outlined in the *Strategic Plan Objectives*. Every Objective in the *2016-2017 Strategic Plan* had associated projects and funding in 2017 and 2018, indicating that the vast majority of priority areas identified by the IACC in the *Strategic Plan Objectives* were also identified as priority areas by federal and private research funders. Each *Strategic Plan Question* has sustained similar proportions of funding throughout the years. In 2017 and 2018, funding toward Question 2 (Biology) continued to be the largest research area funded. Question 3 (Risk Factors) and Question 4 (Treatments and Interventions) had the next largest amounts of funding, as in previous years. Question 7 (Surveillance and Infrastructure) and Question 1 (Screening and Diagnosis) maintained consistent funding levels as years prior. Lastly, Question 5 (Services) and Question 6 (Lifespan Issues) continued to have the smallest amounts of funding, although Question 6 funding grew considerably in 2017 and 2018. This prompted the development of new Question 6 subcategories to describe in more detail the nature of research within this area and enabled the inclusion of subcategory analyses of Question 6 projects in the report for the first time. Also new to the *2017-2018 IACC ASD Research Portfolio Analysis Report* is a comprehensive analysis of the Cross-Cutting Objective on ASD in girls/women. Lastly, the present report introduces a new examination of projects focused on addressing racial, ethnic, geographic, and socioeconomic disparities in ASD, which has been an area of growing interest in ASD research. Each of these new analyses will be tracked in future reports in an effort to understand current trends, highlight potential gaps in research, and identify areas in need of increased research investment.

APPENDICES

APPENDIX A

FEDERAL AGENCY AND PRIVATE ORGANIZATION DESCRIPTIONS

FEDERAL AGENCY AND PRIVATE ORGANIZATION MISSION STATEMENTS

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 Americans and people with disabilities across the lifespan. ACL funds the **AutismNOW** web resource hosted by the Arc, which provides information for the ASD 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 improve the quality, safety, efficiency, and effectiveness of health care for all Americans. Their 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 create the expertise, information, and tools that people and communities need to protect their health. This is achieved through

health promotion, prevention of disease, injury and disability, and preparedness for new health threats. CDC's autism research portfolio includes projects to collect data on ASD prevalence and risk factors, 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 U.S. CDC also funds the **Study to Explore Early Development (SEED)**, which is currently the largest study in the U.S. to help identify factors that may increase the probability of developing autism spectrum disorder and other developmental disabilities.

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. The **Maternal and Child Health Bureau (MCHB)** supports autism-related programs through its Combating Autism Act Initiative (CAAI), 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 evidence-based early 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 mission of NIH is to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability. The NIH supports a broad range of research on ASD, including projects on the basic neuroscience of ASD, risk factors, diagnosis, intervention, 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 ASD. Since 2014, NIH has funded the **ServASD** initiative, which supports research to develop and test the effectiveness of service strategies to improve functional outcomes in early childhood, transition from youth to adulthood, and adulthood. NIH also funds interdisciplinary data repositories such as the **National Database for Autism Research (NDAR)** to facilitate the sharing of autism research data among scientists worldwide.

FEDERAL AGENCIES - OTHER

Department of Defense (DoD)

The Department of Defense (DoD) is charged with coordinating and supervising all agencies and functions of the government concerned directly with national security and the U.S. Armed Forces. Within the DoD's Army Defense Health Research Program, the **Congressionally Directed Medical Research Program's Autism Research Program (ARP)** was established in 2007, with the mission to improve the lives of individuals with ASD by promoting innovative research that advances the understanding of ASD and leads to improved outcomes for those with ASD. The projects that the ARP funds span the scope of the *IACC Strategic Plan*. The U.S. Air Force (DoD-AF) also funds research on ASD and is developing a multidisciplinary autism research and services program for military families, part of which involves the creation of a

comprehensive registry to provide higher quality data for autism clinical and genetics research.

Department of Education (ED)

The mission of the U.S. Department of Education is to promote student achievement by fostering educational excellence and ensuring equal access. The department funds a portfolio of ASD-related projects relating to development and delivery of educational interventions and services, particularly for children and transition-aged 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 U.S. 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 at Davis with the National Institute of Environmental Health Sciences (NIEHS)/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 severity of ASD.

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. Although NSF does not have a program focused on ASD, it funds several projects that involve basic science or technologies with the potential to be applied to ASD in the future. NSF is a leading funder of projects involving technological interventions and supports, including robotics and virtual reality technologies that could be used to enhance daily living skills and activities of individuals with disabilities.

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 spectrum disorders and their families and funds a range of research with a particular emphasis on the 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 ASD. In addition, ASF funds pre- and postdoctoral trainees to conduct basic and clinical research relevant to ASD, including studies focused on a wide range of topics such as identification of biomarkers, molecular and cellular mechanisms, genetic and environmental factors, treatments, and service delivery.

Autism Speaks (AS)

AS is the world's largest autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments, and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families. AS funds a broad profile of ASD 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 Treatment Network**, a collaboration of 14 specialty centers dedicated to providing families with state-of-the-art, multidisciplinary healthcare for children and teens affected by autism.

Brain and Behavior Research Foundation (BBRF)

BBRF 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.

Center for Autism and Related Disorders (CARD)

CARD is one of the world's largest organizations using applied behavior analysis (ABA) in the treatment of ASD and other related disorders. CARD's research portfolio is centered around developing new behavioral interventions, assessing existing behavioral interventions, and developing and implementing training/intervention programs for individuals on the autism spectrum from birth to age 21.

Escher Fund for Autism/Escher Family Fund (EFA)

EFA 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.

Geisinger Autism & Developmental Medicine Institute (GADMI)

GADMI is a transdisciplinary clinical and research institute and an international leader known for advancing the scientific understanding of developmental disorders. In partnership with families, their goal is to leverage new scientific discoveries to transform our understanding of the causes and treatments of these conditions. Their mission is to improve outcomes for individuals with developmental disorders and their families through increased access, accurate diagnosis, discovery of underlying causes, and development of targeted treatments.

New England Center for Children (NECC)

The New England Center for Children 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 under-served children with autism and their families.

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

NJMRTA 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 ASD across their lifespans. The mission of the Council is to advance and disseminate the understanding, treatment, and management of ASD 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 ASD. 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 healthcare decisions and improves healthcare delivery and outcomes by producing and promoting high-integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader healthcare community.

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

The mission of SF is to advance the frontiers of research in mathematics and the basic sciences. SF's single largest initiative is SFARI, which seeks to improve the diagnosis and treatment of ASD by funding, catalyzing, and driving innovative research of the greatest quality and relevance. The SF ASD portfolio includes research on genetic and cellular factors underlying autism, identification of genetic and environmental risk factors, 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.

Tuberous Sclerosis Alliance (TSA)

TSA 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, their 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 ASD, and it is a leading genetic cause of syndromic autism. TSA funds research that focuses on the connection between ASD and TSC.

APPENDIX B

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 features of autism. 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 U.S.

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.

Intermediate 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.

Symptomology

These projects seek to define the broad range and severity 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 and language. Other projects seek to understand the emergence of problem behaviors and how neurocognitive differences can contribute to developmental and phenotypic variability in those with an autism diagnosis.



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 and empathy, understanding facial expressions of emotion (and how and why this is impaired in ASD), 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 conditions that often co-occur with ASD is included here, such as seizures/epilepsy, sleep disorders, gastrointestinal dysfunction, wandering/elopement behavior, attention deficit hyperactivity disorder (ADHD), and familial autoimmune disorders.

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 ASD to typically developing children or to their unaffected siblings.

Immune/Metabolic pathways

These projects focus on understanding the biological mechanisms of metabolism and the immune system that may be altered in autism, typically in cells and animal models. This largely includes studies on inflammation and inflammatory molecules (i.e., cytokines), as well as on the role of mitochondria, energy metabolism, and oxidative stress. Also included in this group are projects seeking to identify specific immune and metabolic mechanisms underlying specific triggers in early prenatal and post-natal life, such as maternal infection, maternal auto-antibodies, and toxic 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 ASD 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 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 ASD individuals. 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 ASD 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 understand some of the underlying biology in ASD. This can be done by searching for certain biological factors (“signatures”), such as hormone levels or structural abnormalities 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: RISK FACTORS

Environmental risk factors

This subcategory includes a number of projects investigating potential environmental factors that may contribute to the development of autism. Example projects include studies of the effects of the microbiome, environmental contaminants and toxins, maternal dietary

factors, medications taken during pregnancy or to induce labor, assistive reproductive treatments, child and maternal response to immune challenge, and registries where many of these factors can be tracked simultaneously.

Epigenetics

Epigenetics is the study of heritable changes in gene function that occur without a change in the DNA sequence (such as methylation of DNA). Environmental factors can cause these changes in gene expression, and projects in this subcategory seek to identify some of the environmental influences that may lead to these epigenetic changes.

Gene-Environment

These studies include efforts to identify and understand the contributions of environmental factors, genetic susceptibility, and human physiology (e.g., the immune system, metabolic processes) that may increase the probability of developing ASD, as well as studies that directly examine gene-environment interactions. (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 risk factors

Projects in this subcategory seek to identify new genes that are implicated in higher probability of developing ASD or to better understand genetic factors that were previously identified.



QUESTION 4: TREATMENTS AND INTERVENTIONS

Behavioral

Projects in this subcategory involve a wide array of behavioral research and training methods, including applied behavior analysis (ABA), 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. Projects in this subcategory may include research focused on the outcome measures of behavioral interventions.

Complementary, dietary, and alternative

This subcategory includes research on acupuncture; acupressure; antioxidants; cholesterol supplementation; glutathione metabolism; 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. Projects in this subcategory may include research focused on the outcome measures of educational interventions.

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 mimicking behaviors of ASD 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 interventions and supports

Augmentative and alternative communication (AAC), computer applications and software, picture exchange communication system (PECS), social robots, teleconferencing, 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. Projects in this subcategory may include research focused on the outcome measures of technology-based interventions.



QUESTION 5: SERVICES

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 ASD and their families, as well as assess programs to help parents navigate the service system after their child receives an ASD diagnosis. It also surveys safety issues for those with autism, including wandering and bullying.

Practitioner training

Projects in this subcategory seek to increase skill levels in service providers, including medical 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, a comprehensive online resource 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 racial and ethnic minorities.



QUESTION 6: LIFESPAN ISSUES

Although Question 6 is still the research area with the smallest proportion of research funding, in recent years there has been an increase in funding and project counts aligned with lifespan issues. Based on the increase in projects and discussions at IACC meetings, OARC developed Question 6 subcategory coding for the *2017-2018 IACC Portfolio Analysis Report*. While many Question 6 topics tend to cover more than one research topic, projects were assigned to one subcategory code that aligned most with the project's goals. The five new Question 6 subcategories are:

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 category will also include any sibling and caregiver engagement services and interventions.

Health and behavioral outcomes

Projects in this subcategory focus on understanding and improving health-related outcomes for youth and adults, including treatment of core features and co-occurring conditions, behavioral outcomes, and other longitudinal studies.

**Improving healthcare systems/
Healthcare transitions**

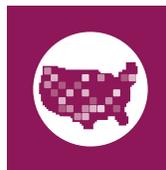
These projects are focused on efforts to improve provider-patient experiences and interactions across the lifespan; this category includes screening and diagnostic tools focused on youth and adults (not solely ASD-specific tools).

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 ASD.

**Transition to adulthood and
post-secondary 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 category also focuses on young adulthood and projects that support post-secondary outcomes such as college experiences, employment, and quality of life.

**QUESTION 7:
INFRASTRUCTURE AND
SURVEILLANCE****Biobanks**

A biobank is a type of biorepository which stores human biological samples for use in research. Projects in this subcategory support 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, as well as dissemination of data to the community and stakeholders.

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 ASD field are included in this subcategory.

Surveillance and prevalence studies

Research that measures autism prevalence in the U.S. and internationally is contained in this subcategory, including the Autism and Developmental Disabilities Monitoring (ADDM) Network sites maintained by the Centers for Disease Control and Prevention (CDC).

APPENDIX C

ASD-RELATED RESEARCH PROJECTS NOT INCLUDED IN THE *IACC PORTFOLIO ANALYSIS*

In previous *IACC Portfolio Analysis Reports*, an appendix on ASD-related research projects has been included as reference material for stakeholders, researchers, and funders. This lists projects that are not specifically focused on autism but may be helpful in understanding the broader landscape of ongoing research on disabilities and other topics that may be relevant to autism. When the 2017 and 2018 portfolio data were collected, this list had grown to include hundreds of projects. In an effort to keep the published *IACC Portfolio Analysis Reports* concise, this list of projects is now available on our website at the following link

and QR code. If you are interested in viewing the list of ASD-related research projects for 2017 and 2018, please visit the webpage below.

Direct link to ASD-Related Research Projects:
<https://iacc.hhs.gov/publications/portfolio-analysis/2018/asd-related-projects.shtml>



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