

2016 IACC AUTISM SPECTRUM DISORDER RESEARCH

PORTFOLIO ANALYSIS REPORT



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

INTERAGENCY AUTISM COORDINATING COMMITTEE

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Cover Design

Medical Arts Branch, Office of Research Services, National Institutes of Health

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Suggested Citation

Office of Autism Research Coordination, National Institute of Mental Health, on behalf of the Interagency Autism Coordinating Committee (IACC). *2016 IACC Autism Spectrum Disorder Research Portfolio Analysis Report*. January 2019. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: <https://iacc.hhs.gov/portfolio-analysis/2016/index.shtml>

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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 2014.

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 to HHS and partners with other federal departments, federal 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 www.iacc.hhs.gov.

INTRODUCTION & ANALYSIS FRAMEWORK

In 2009, the Interagency Autism Coordinating Committee (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. The *IACC Strategic Plan*, developed with extensive input from a broad array of federal and public stakeholders, organizes research priorities around seven general topic areas represented as community-focused “questions.” The questions are divided further into research objectives that address key research needs, gaps, and opportunities identified by the Committee. For the most recent edition, **2016-2017 IACC Strategic Plan for Autism Spectrum Disorder**, the Committee agreed that given the recent advances in the autism field, it was an appropriate time to re-evaluate the autism research landscape and formulate new objectives for each question. Each question in the *Strategic Plan* includes three to four primary objectives; there is also one cross-cutting objective on the topic of ASD in females. The 23 new objectives on autism research and services are presented in **Figure 1**; 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*.

Following the development of the *IACC Strategic Plan*, the Office of Autism Research Coordination (OARC) – the office within the National Institutes of Health (NIH) that manages the activities of the IACC – began in 2008 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 U.S. The 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 efforts and track progress made each year on the objectives in the *IACC Strategic Plan*. The *2016 Portfolio Analysis Report* is the first portfolio analysis measuring progress made toward the 22 primary objectives and one cross-cutting objective in the *2016-2017 IACC Strategic Plan*. In addition to information on research progress made in 2016, the *2016 IACC ASD Research Portfolio Analysis Report* also provides an analysis of progress that was made over the nine-year period from 2008-2016.

To accompany the *IACC 2016 ASD Research Portfolio Analysis Report*, detailed federal and private organization project data are available in the Autism Research Database (ARD), a database 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.

2016-2017 STRATEGIC PLAN OBJECTIVES



Question 1: HOW CAN I RECOGNIZE THE SIGNS OF ASD, AND WHY IS EARLY DETECTION SO IMPORTANT?

- 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 ADS to early, targeted interventions and supports.

CROSS-CUTTING

- 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?

- 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 DISABLING ASPECTS OF ASD BE PREVENTED OR PREEMPTED?

- 1 Strengthen understanding of genetic risk and resilience 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 risk and resilience 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 risk and resilience factors interact through specific biological mechanisms to manifest in ASD phenotypes.



Question 4: WHICH TREATMENTS AND INTERVENTIONS WILL HELP?

- 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?

- 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?

- 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?

- 1 Promote growth, integration, and coordination of 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 2016-2017 IACC Strategic Plan's revised seven questions and 23 new objectives.

IACC Strategic Plan Questions and Corresponding Research Areas

The Office of Autism Research Coordination (OARC) requested information on 2016 autism-related research projects funded by several 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*, illustrated below (**Figure 2**).

IACC STRATEGIC PLAN QUESTIONS AND CORRESPONDING RESEARCH AREAS



Figure 2. The seven questions and corresponding research areas of the *2016-2017 IACC Strategic Plan* are represented by the icons to the left of each question.

Subcategory Classification

In 2010, OARC introduced the subcategory classification system (**Figure 3**) 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 in the *2016 Portfolio Analysis Report* was assigned to a

subcategory based on the research area it addressed. The application of subcategory coding to projects in the portfolio helped to break the portfolio into easy-to-understand topical areas. For example, within Question 1 (Screening and Diagnosis), the projects were divided into four subcategories: 1) Diagnostic and screening tools; 2) Early signs and biomarkers; 3) Intermediate phenotypes/ Subgroups and 4) Symptomology.

IACC STRATEGIC PLAN CORRESPONDING RESEARCH AREAS BY SUBCATEGORY

Screening & Diagnosis	Biology	Risk Factors	Treatments & Interventions	Services	Lifespan Issues	Infrastructure & Surveillance
<p>Subcategories</p> <ul style="list-style-type: none"> * Early signs and biomarkers * Diagnostic and screening tools * Intermediate phenotype/ subgroups * Symptomology 	<p>Subcategories</p> <ul style="list-style-type: none"> * Cognitive studies * Computational science * Co-occurring conditions * Developmental trajectory * Immune/metabolic pathways * Molecular pathways * Neural systems * Neuropathology * Sensory and motor function * Subgroups/ biosignatures 	<p>Subcategories</p> <ul style="list-style-type: none"> * Genetic risk factors * Environmental risk factors * Epigenetics * Gene-environment 	<p>Subcategories</p> <ul style="list-style-type: none"> * Technology-based intervention and supports * Behavioral * Complementary, dietary, and alternative * Educational * Medical/ pharmacologic * Model systems/ therapeutic targets * Occupational, physical, and sensory-based 	<p>Subcategories</p> <ul style="list-style-type: none"> * Services utilization and access * Community inclusion programs * Efficacious and cost-effective service delivery * Family well-being and safety * Practitioner training 	<p>Subcategories</p> <ul style="list-style-type: none"> * No subcategories created due to small number of projects. Subcategories may be established in the future. 	<p>Subcategories</p> <ul style="list-style-type: none"> * Biobanks * Data tools * Research infrastructure * Surveillance and prevalence studies * Research workforce development * Research recruitment and clinical care

Figure 3. A subcategory classification system was created to allow an understanding of the autism research portfolio based on simple research topics that are relevant to each of the *IACC Strategic Plan* questions. Appendix C provides detailed definitions of the subcategory research areas.

ASD RESEARCH FUNDERS AND FUNDING IN 2016

Who funded ASD research in 2016?

Nine federal agencies and nine private funders provided their autism research funding information for this analysis. These 18 agencies and organizations are listed in **Table 1**. There were no new agencies or organizations added for the 2016 ASD research portfolio. Some agencies and organizations included in previous years'

analyses did not have projects to report in 2016 or chose not to participate in this year's analysis. Brief summaries of the mission areas for each agency and organization that contributed to the *2016 Portfolio Analysis* can be found in **Appendix A** of this report.

AGENCIES AND ORGANIZATIONS INCLUDED IN THE 2016 IACC PORTFOLIO ANALYSIS

FEDERAL AGENCIES	PRIVATE ORGANIZATIONS
<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) New England Center for Children (NECC) Organization for Autism Research (OAR) Patient-Centered Outcomes Research Institute (PCORI) Simons Foundation (SF)

Table 1. Projects from nine federal agencies and nine private organizations were included in the *2016 IACC ASD Research Portfolio Analysis Report*.

How much ASD research was funded in 2016?

Combined, the estimated federal and private investment in ASD research in 2016 was \$364,435,254. The overall funding for autism research increased by \$14.1 million from 2015 to 2016. However, the relative proportions contributed by federal and private funders during this period were relatively unchanged from the previous

year. In 2016, the federal government provided \$291.7 million in ASD research funding and accounted for 80% of overall funding. Private organizations provided \$72.7 million in funding, which accounted for 20% of the total funding in 2016 (**Figure 4**).

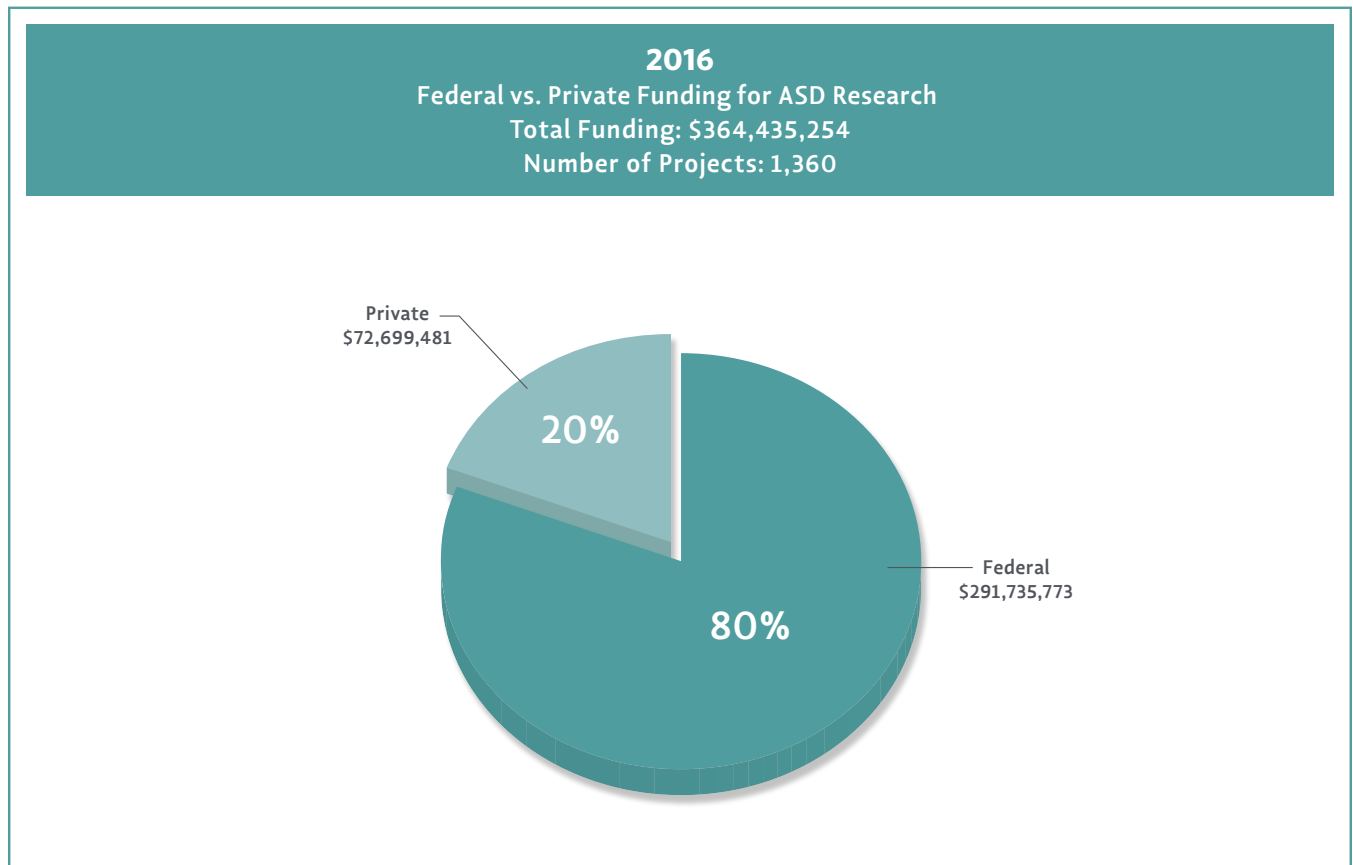


Figure 4. In 2016, 80% of ASD research was provided by federal sources, while 20% of funding was provided by private organizations.

What funding trends were observed?

- ASD research funding increased from 2015-2016. In 2015, combined federal and private investment in ASD research was \$342.7 million. In 2016, the combined federal and private funding was \$364.4 million, an increase of 6.3% over one year (**Figure 5**).
- Federal investment in ASD research increased 5.1% in 2016 (\$291.7 million) from 2015 (\$277.6 million).
- The amount of private investment in ASD research reported in 2016 (\$72.7 million) was significantly higher, 11.7%, than in 2015 (\$65.1 million).
- 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 rising over recent years. Funding in 2016 was slightly higher than the 2010 non-ARRA funding level and is the highest year of funding since 2010.

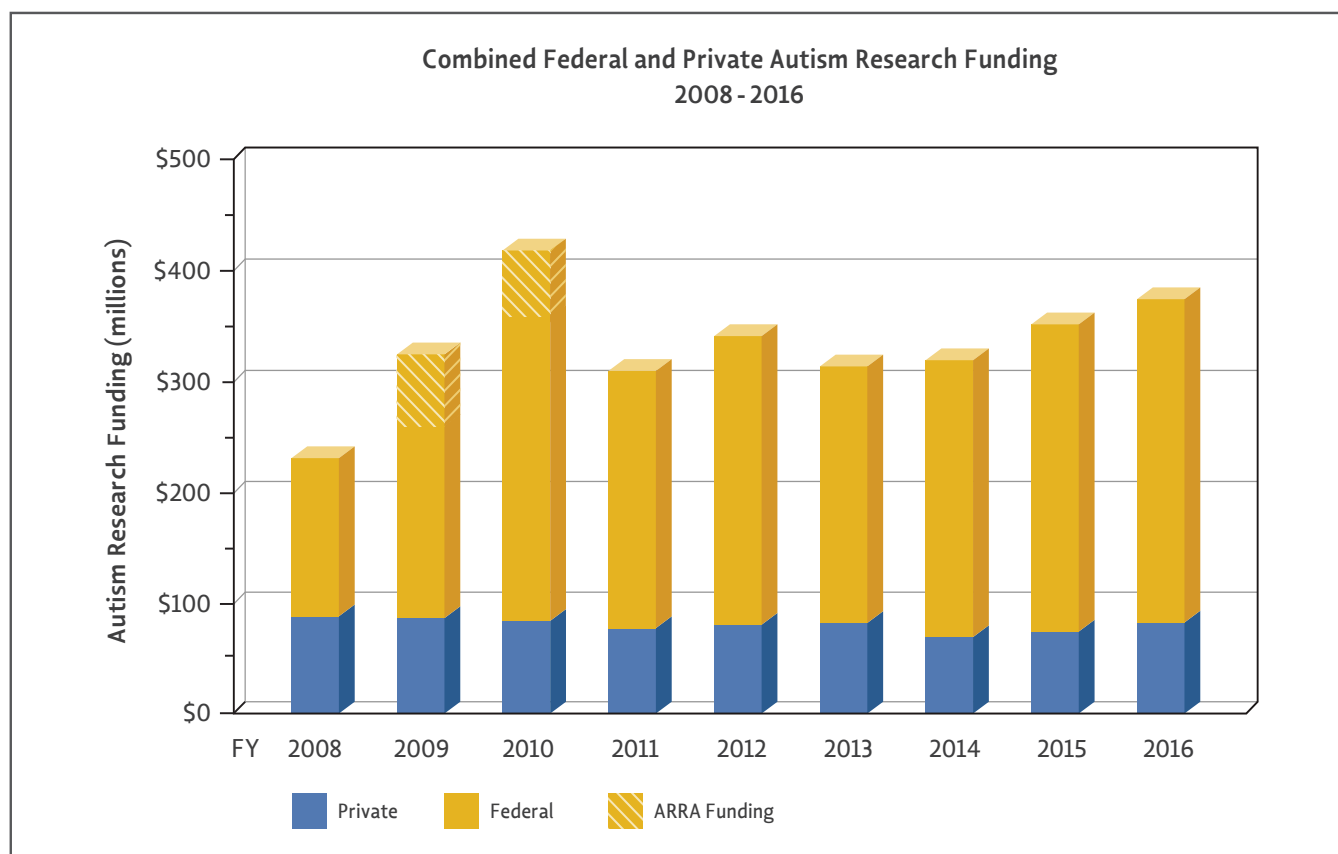


Figure 5. This figure illustrates levels of autism research funding from combined federal and private sources during 2008-2016 based on data collected for the *IACC Portfolio Analysis* of those years.

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 2016. 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 are University of California at Davis, Yale University, and University of California at Los Angeles. University of California at Davis has many investigators collaborating on major research initiatives such as the **Baby Siblings Consortium**, **SPARK**, and the **Childhood Autism Risks from Genetics and Environment (CHARGE) study**. It is also the site of the **UC Davis Mind Institute** and the **UC Davis Center for Children's Environmental Health and Disease Prevention (CCEH)**. 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**. University of California at Los Angeles has investigators involved in the Autism Intervention Research Network on Behavioral Health (**AIR-B network**) and the Health Care Transitions Research Network (**HCT-RN**) for youth and young adults with 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 studied. **Table 2** provides some additional information about the institutions and states that had the largest number of projects in 2016.

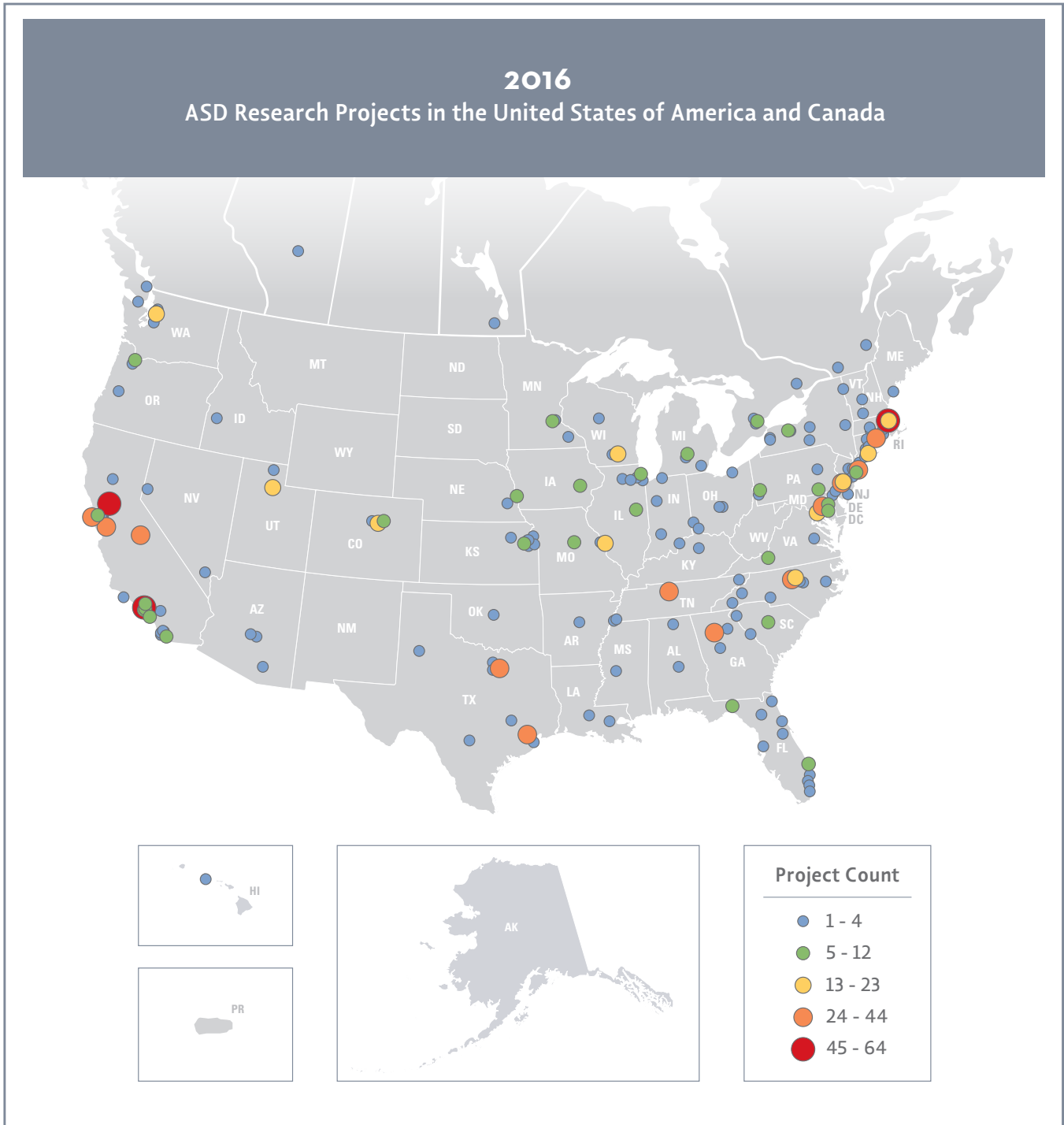


Figure 6. A map of the U.S. and Canada displaying the distribution of autism-related research projects in 2016 funded by federal agencies and private organizations.

<i>Which U.S. institutions had the highest levels of funding in 2016?</i>		
Institution	Funding	Project Count
University of California, Davis	\$ 18,355,969	54
Yale University	\$ 15,308,925	41
University of California, Los Angeles	\$ 15,010,953	44
National Institutes of Health - Intramural Research Program	\$ 13,085,768	12
University of North Carolina at Chapel Hill	\$ 10,481,404	34
New York Genome Center, Inc.	\$ 9,824,025	1
Boston Children's Hospital	\$ 9,269,892	22
Stanford University	\$ 8,620,483	30
University of California, San Diego	\$ 8,337,640	28
Massachusetts Institute of Technology	\$ 6,809,803	13

<i>Which states had the highest levels of funding in 2016?</i>		
State	Funding	Project Count
California	\$ 71,970,228	261
New York	\$ 46,215,102	133
Massachusetts	\$ 44,289,321	202
Maryland	\$ 33,126,572	62
Pennsylvania	\$ 18,526,114	77
North Carolina	\$ 18,014,641	61
Connecticut	\$ 16,254,794	46
Georgia	\$ 11,821,168	50
Florida	\$ 9,867,385	32
Texas	\$ 9,603,843	40

Table 2. Institutions and states with the most ASD-related research funding from federal and private sources in 2016.

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

While majority of the U.S. ASD research funding is awarded to investigators at U.S. institutions, several of the agencies and organizations from which IACC/OARC collects information invest in ASD research internationally. In 2016, 19 countries outside the U.S. received funding for ASD research from agencies and organizations represented in the *Portfolio Analysis*, with total funding of international projects amounting to \$3.6 million and 50 projects were funded. Overall, 1% of total funding went towards institutions outside of the U.S. and 3.7% of all projects were at international institutions. While a few federal agencies funded projects at international institutions, most of the international research was supported by private organizations (**Table 3**). The countries that received the largest portion of international funding were Canada and the United Kingdom (**Table 4**).

<i>Funders supporting International ASD Research in 2016</i>	
New England Center for Children	Autism Science Foundation
Brain & Behavior Research Foundation	Simons Foundation
Autism Speaks	Department of Defense - Army
National Institutes of Health	

Table 3. List of funders who provided funding for international ASD research in 2016.

COUNTRIES THAT RECEIVED ASD RESEARCH FUNDING FROM U.S. FUNDERS

Country	Funding Amount	Project Count
Australia	\$239,576	4
Austria	\$99,730	1
Belgium	\$117,500	1
Canada	\$1,910,931	20
China	\$5,000	1
France	\$52,500	2
Germany	\$86,948	2
Ireland	\$0	1
Israel	\$0	1
Italy	\$102,436	2
Netherlands	\$125,000	1
Pakistan	\$250,000	1
Portugal	\$5,000	1
Spain	\$32,158	1
Switzerland	\$0	2
Taiwan	\$70,000	1
Turkey	\$70,000	1
United Arab Emirates	\$1,830	1
United Kingdom	\$414,187	6
Total	\$3,582,796	50

Table 4. List of countries that received funding from U.S. federal agencies or private organizations to support ASD research.

How much ASD research funding did each funder provide in 2016?

The 18 agencies and organizations that participated in the *2016 Portfolio Analysis* supported 1,360 ASD research projects totaling \$364,435,254 (**Table 5**).

The National Institutes of Health (NIH) was the leading federal (and overall) funder of ASD research in 2016 with a total of \$234.4 million, funding 547 projects. NIH funding for autism research increased by \$17.7 million from 2015 to 2016. The next largest federal funder was the Department of Education (ED), with \$19.6 million, followed by the Centers for Disease Control

and Prevention (CDC), with \$15.4 million. ED's research funding decreased by \$6.7 million, due to several large, ongoing projects that received large amounts of funding in 2015 but did not receive an increment in 2016. The CDC's funding stayed relatively the same from 2015 to 2016. As in previous years, the Simons Foundation and Autism Speaks were the largest private funders of ASD research in 2016, with investments of \$61.8 million and \$6.7 million, respectively. The percentage of overall ASD research funding provided by each agency is depicted in **Figure 7**.

2016 ASD RESEARCH FUNDING BY AGENCY/ORGANIZATION

Funding Agency/Organization	2016 Funding	Project Count
National Institutes of Health (NIH)	\$234,392,406	547*
Simons Foundation (SF)	\$61,754,800	283
Department of Education (ED)	\$19,627,374	75
Centers for Disease Control and Prevention (CDC)	\$15,390,203	28
Health Resources and Services Administration (HRSA)	\$8,576,199**	30
Department of Defense - Army (DoD-Army)	\$6,888,542	58
Autism Speaks (AS)	\$6,745,989	90
National Science Foundation (NSF)	\$4,488,826	44
Administration for Community Living (ACL)	\$1,798,164	7
Brain & Behavior Research Foundation (BBRF)	\$1,688,387	56
Patient-Centered Outcomes Research Institute (PCORI)	\$539,719	7
Center for Autism and Related Disorders (CARD)	\$690,000	9
Autism Science Foundation (ASF)	\$474,072	30
Environmental Protection Agency (EPA)	\$420,364	1
Autism Research Institute (ARI)	\$347,650	8
New England Center for Children (NECC)	\$259,060	64
Organization for Autism Research (OAR)	\$199,803	19
Agency for Healthcare Research and Quality (AHRQ)	\$153,695	4
Grand Total	\$364,435,254	1,360

*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 5. The table lists the total funding and number of projects provided by the 18 federal agencies and private organizations included in the *Portfolio Analysis* for 2016. Together, the agencies and organizations funded 1,360 projects, representing an overall investment of \$364,435,254.

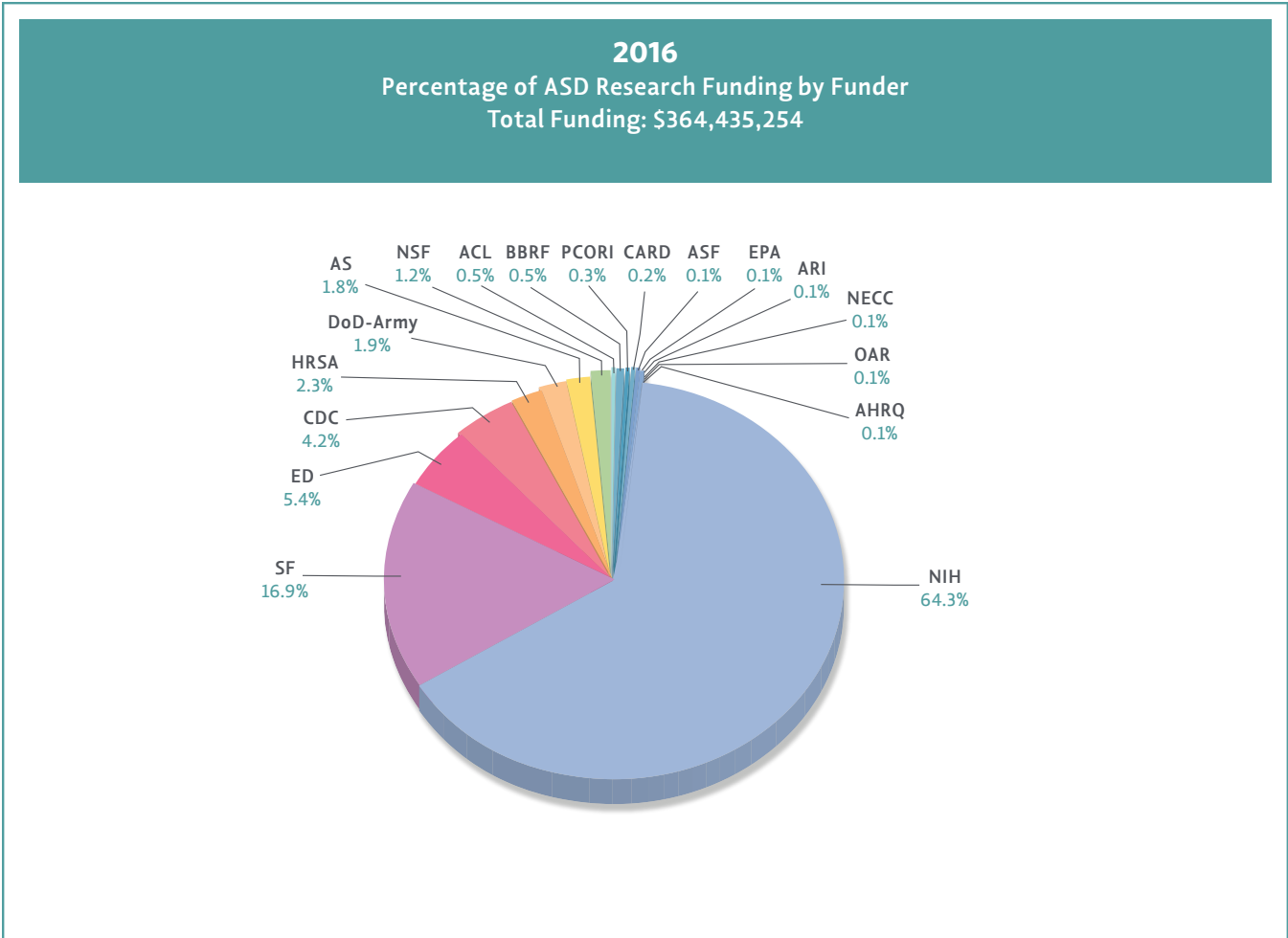


Figure 7. The figure illustrates the percentage of total ASD research funding contributed by the 18 federal agencies and private organizations included in the 2016 portfolio. NIH provided the largest proportion of funding (64.3%), while Simons Foundation provided the largest private investment (16.9%).

Summary of ASD Research Funding in 2016

The recently published *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 Committee recommended a nearly 15% annual increase in ASD research funding. Since the *2014-2015 Portfolio Analysis Report*, funding for autism research increased from \$342.7 million to \$364.4 million in 2016, representing a 6.3% increase in funding. While this did not achieve the *2016-2017 IACC Strategic Plan* recommended funding amount of \$394 million, ASD research did experience a substantial growth in funding for 2016 (**Figure 8**).

Over the nine-year span from 2008-2016, funding increased by 64%, suggesting a continued overall growth in support of ASD research. However, over the period from 2008 to 2016, ASD funding has grown, while

undergoing some fluctuations from one year to the next (**Figure 5**). Autism research reached a peak in funding (including ARRA funds) in 2010 and then experienced lower, but overall increasing levels of funding over the next few years. In 2016, the ASD research portfolio was funded at the highest level since 2010, but 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.

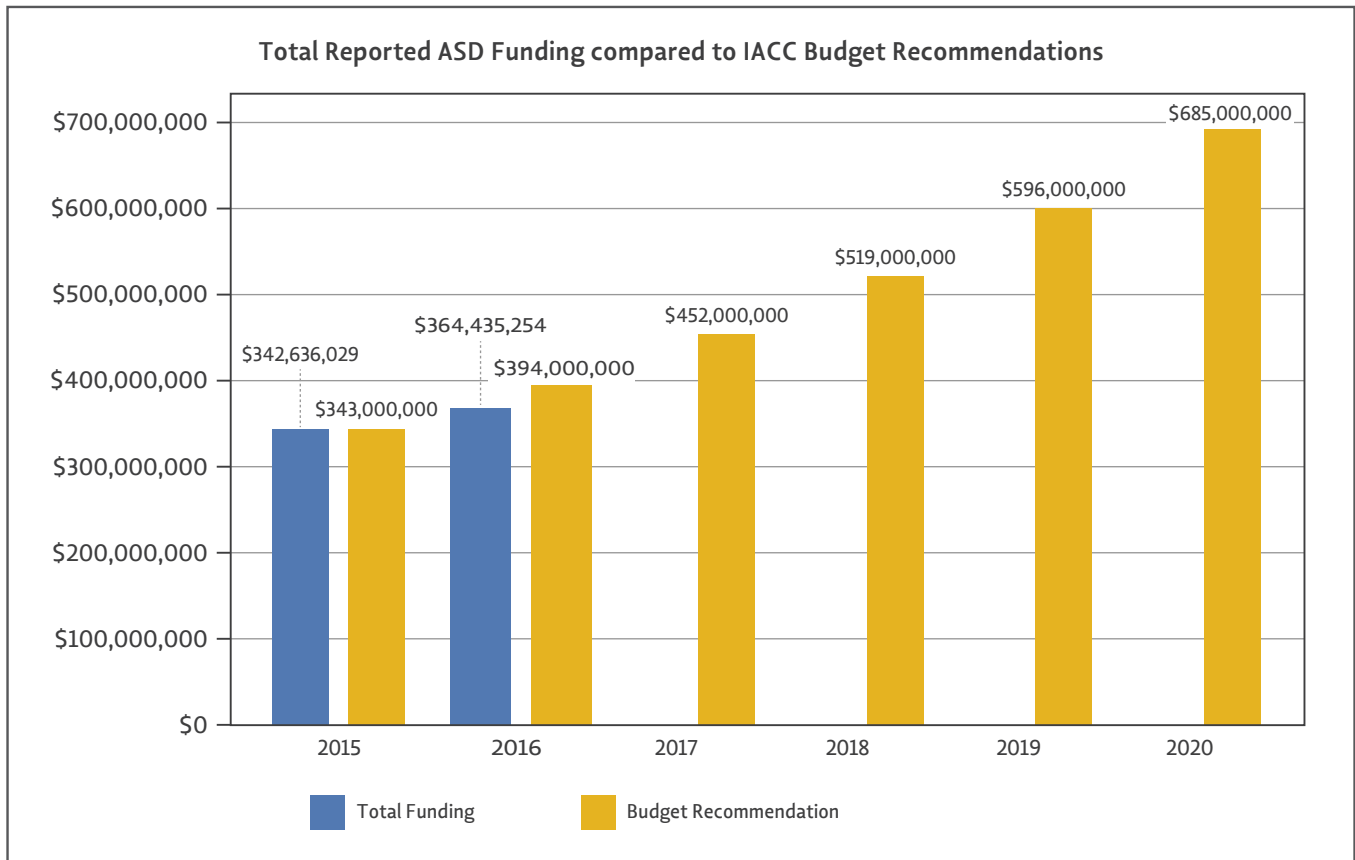


Figure 8. The IACC recommends a doubling of the combined federal and private ASD research budget to \$685 million by 2020. Based on 2015 and 2016 funding amounts, ASD research investment is lagging behind IACC budget recommendations.

ASD RESEARCH AREAS AND PROGRESS IN 2016

What areas of ASD research were funded in 2016?

To better understand what areas of research were funded in 2016, projects were aligned with the questions in the *2016-2017 IACC Strategic Plan*. **Figure 9** illustrates 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.

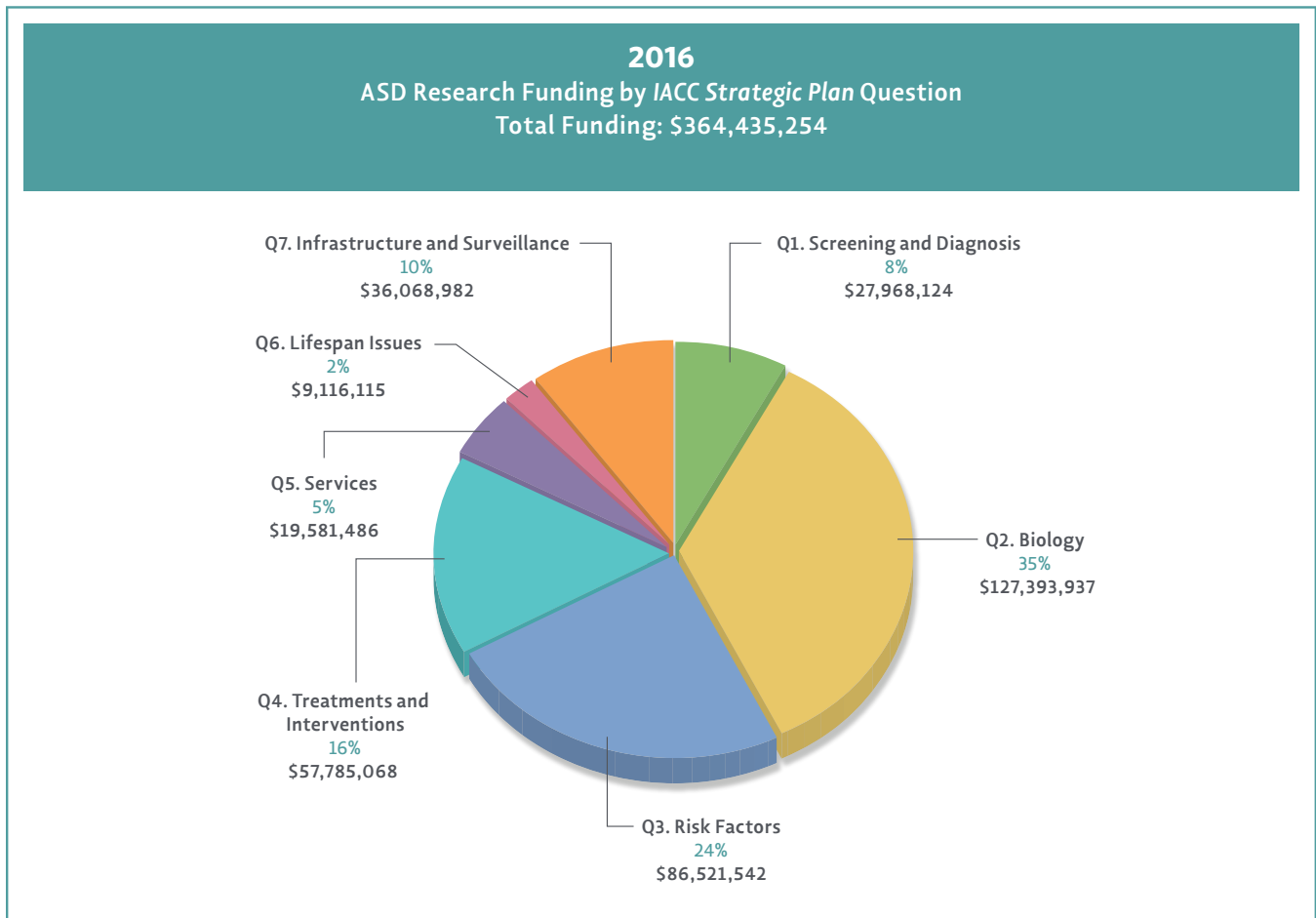


Figure 9. Topic areas are defined by each question in the *IACC Strategic Plan*. The seven questions of the *Strategic Plan* are represented in the clockwise direction, beginning with Screening and Diagnosis (**Question 1**) and ending with Infrastructure and Surveillance (**Question 7**).

ASD research funding in 2016 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 (Question 2) of ASD (35%). This was followed by Question 3 (Risk Factors), research aimed at identifying potential causes and risk factors for ASD (24%). While Question 3 was the second highest funded research question in 2015, it saw a significant increase in its portion of funding in 2016 compared to 2015 (18%). Research into treatments and interventions for ASD (Question 4), including behavioral therapies, pharmacological treatments, and technology-based interventions, followed with 16% of total funding in 2016 – which was relatively the same as previous years. Investment in research infrastructure and surveillance (Question 7) was 10%, a slight decrease from 2015 (16%). Research to improve screening and diagnosis of ASD (Question 1) was comparable to previous years with 8% of research funding in 2016. Research focused on services (Question 5) and lifespan issues (Question 6) remained the smallest areas of funding. Question 5 was 5% of ASD research funding and Question 6 was 2% of funding. For Questions 5 and 6, the percentages of funding

were similar to those seen in 2015. Some shifts in funding and project distribution among the question areas were related to the new objectives of the *2016-2017 Strategic Plan*; these observations will be discussed in more detail in the specific question chapters.

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 2016, the percentage of total projects aligned with each question were as follows: Question 1, 8%; Question 2, 36%; Question 3, 18%; Question 4, 19%; Question 5, 6%; Question 6, 3%; Question 7, 10% (**Figure 10**). The proportion of projects stayed relatively constant from previous years, however, Question 4 did see a significant drop in its percentage of the project count total. This decrease is due to the new *2016-2017 Strategic Plan* objectives, in which some projects previously assigned to Question 4 were better suited in other question areas due to the new objectives' aims. This will be addressed in Question 4's section of the report.

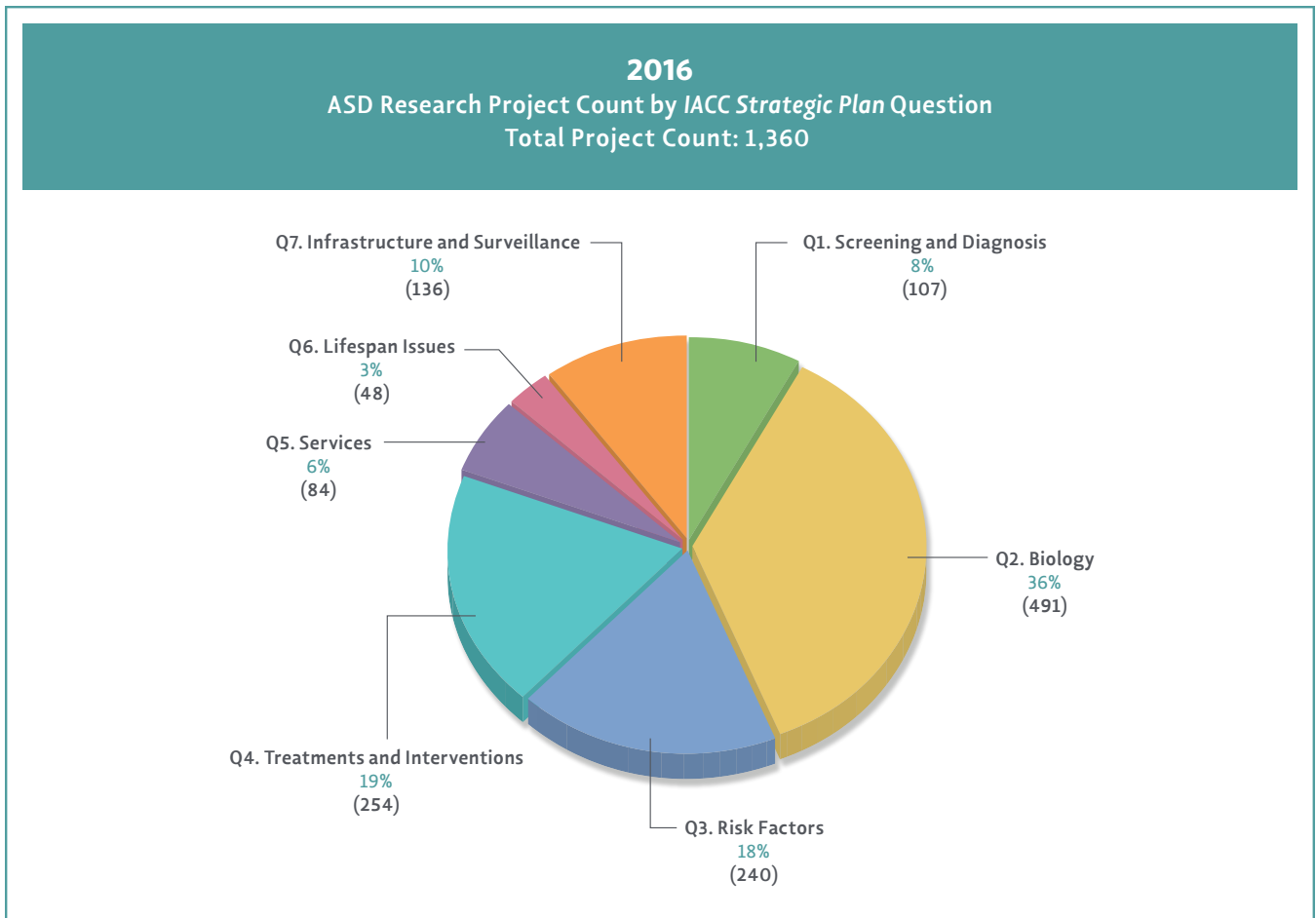


Figure 10. 2016 projects aligned to Strategic Plan questions.

How many new research projects were added in 2016 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 current year of analysis. In 2016, approximately 71% of overall ASD research funding went to ongoing projects while 29% went to new projects. Since most research projects are funded over multiple years, a larger number of ongoing projects compared with new projects is expected. Research related to lifespan issues (Question 6) had higher proportions of funding devoted to new projects compared to the other question areas. 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 services (Question 5) had a higher portion of funding going to ongoing projects when compared to other questions. Question 1 and Question 5 could be expected to have more ongoing projects in 2016 since each question had a greater percentage of new projects in 2015 (Question 1, 28% in 2015; Question 5, 30% in 2015) (Figure 11).

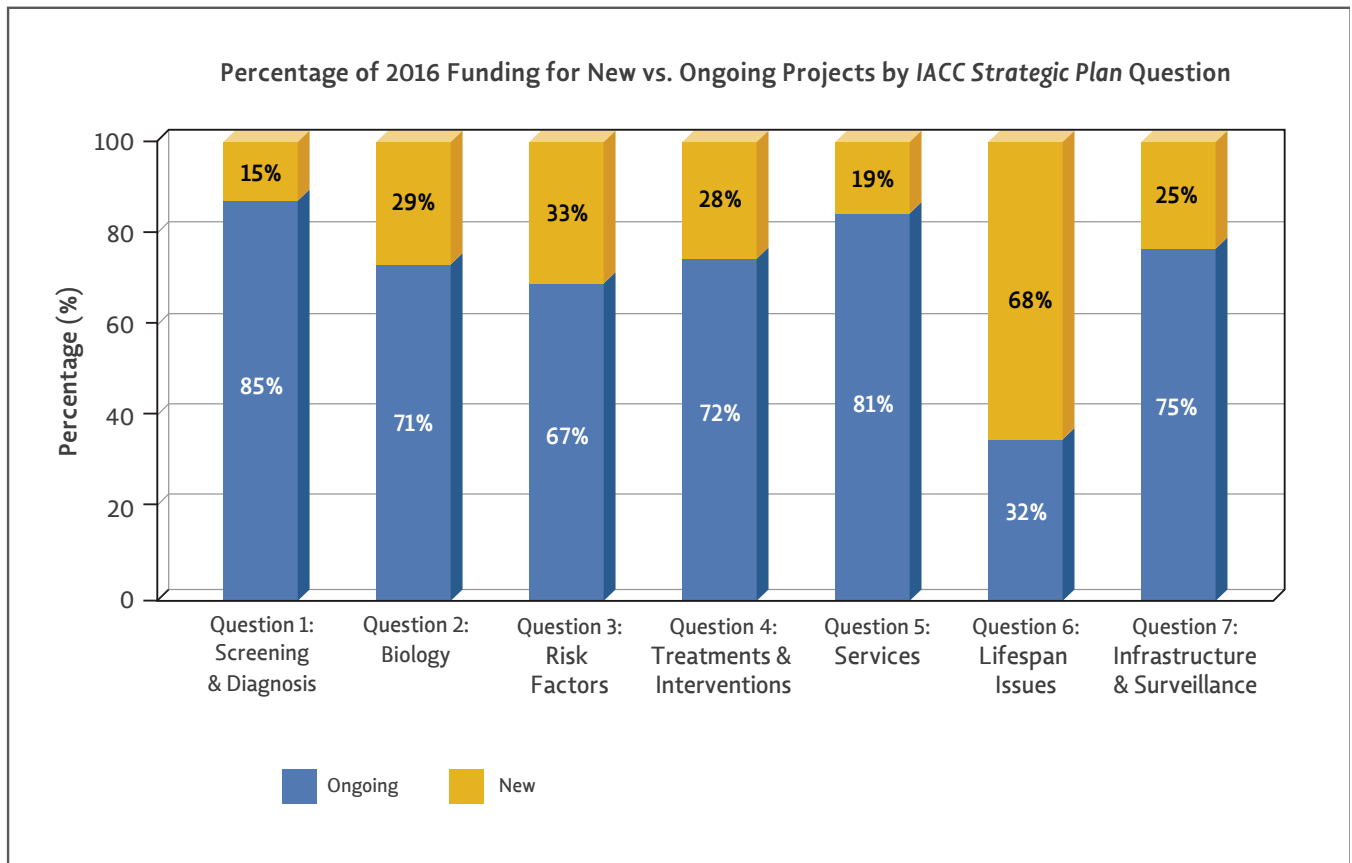


Figure 11. The percentages of ASD research funding going to ongoing versus new projects varies between *Strategic Plan* questions in 2016.

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 12**, federal and private funders contributed to funding for each of the question areas in the *IACC Strategic Plan for ASD* in 2016. 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. For example, infrastructure and surveillance projects (Question 7) received nearly equal support from federal and private sources, while research on screening and diagnosis

(Question 1) and treatments and interventions (Question 4) are largely supported by funding from federal sources. **Figure 13** shows the agencies and organizations that funded projects in 2016 in each of the seven question areas of the *IACC Strategic Plan*. **Figure 14** provides a graphic illustrating the breadth of the mission areas of the funding agencies and organizations included in the *IACC Portfolio Analysis Report*. 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.

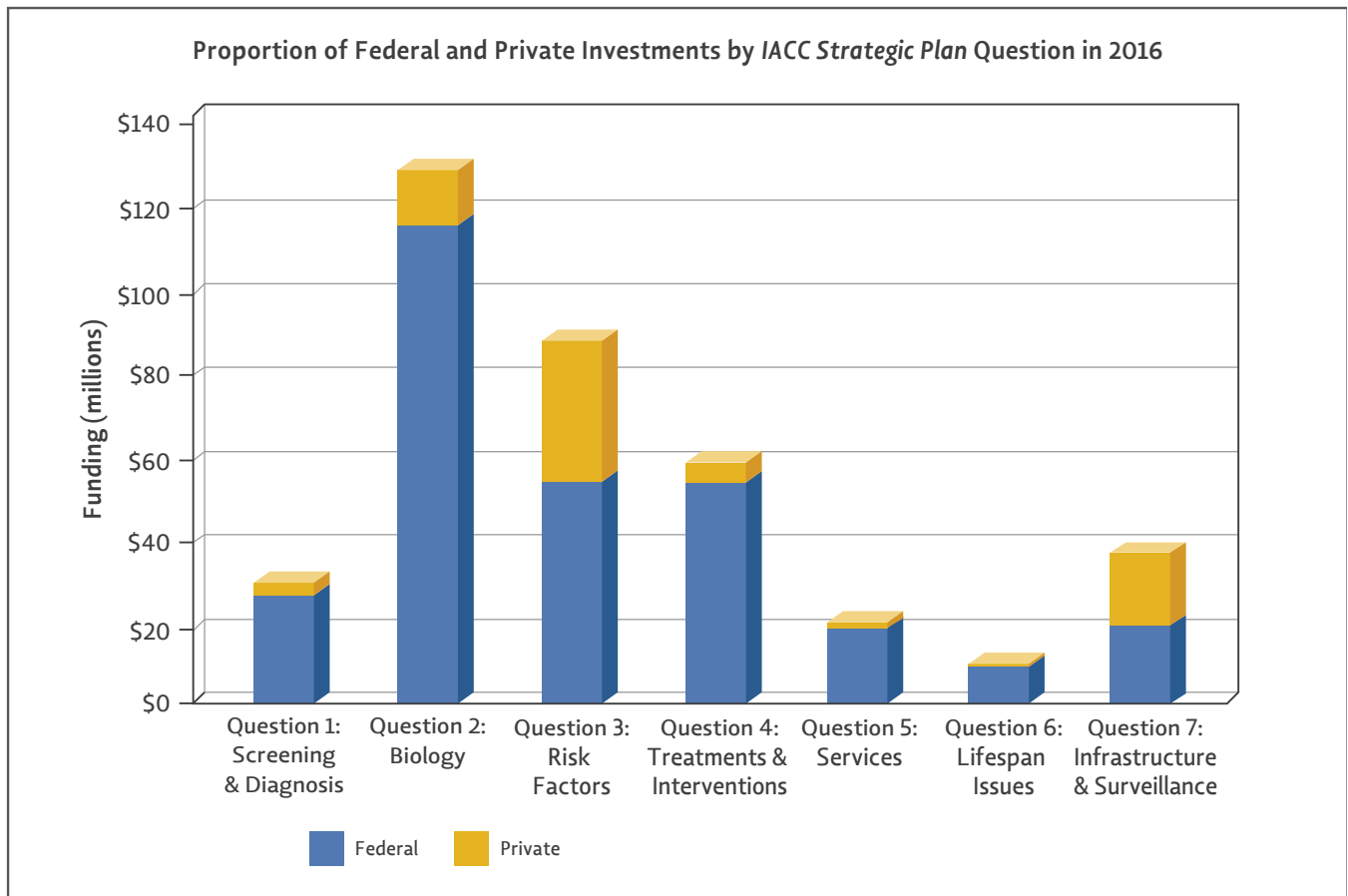
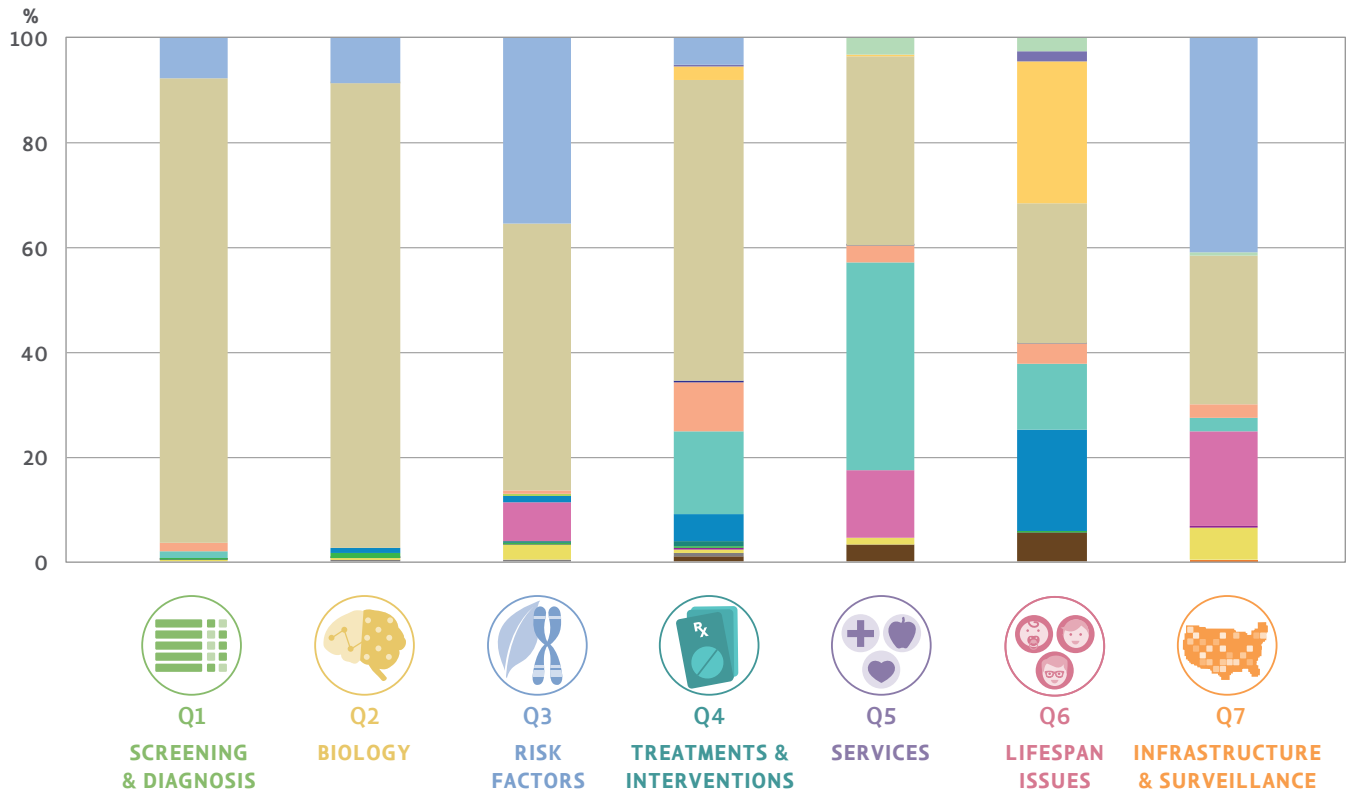


Figure 12. Federal and private funding was provided for each *Strategic Plan* question area in 2016, although the proportion of federal versus private funding varied between question areas.

2016 Funder Contributions to Strategic Plan Questions



ORGANIZATION

- | | | |
|---|---|---|
| <ul style="list-style-type: none"> ■ Administration for Community Living (ACL) ■ Agency for Healthcare Research and Quality (AHRQ) ■ Autism Research Institute (ARI) ■ Autism Science Foundation (ASF) ■ Autism Speaks (AS) ■ Brain & Behavior Research Foundation (BBRF) ■ Center for Autism and Related Disorders (CARD) | <ul style="list-style-type: none"> ■ 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) | <ul style="list-style-type: none"> ■ National Science Foundation (NSF) ■ New England Center for Children (NECC) ■ Organization for Autism Research (OAR) ■ Patient-Centered Outcomes Research Institute (PCORI) ■ Simons Foundation (SF) |
|---|---|---|

Figure 13. The proportion of each federal agency and private organizations' funding in the portfolio analysis organized by IACC Strategic Plan question for 2016.

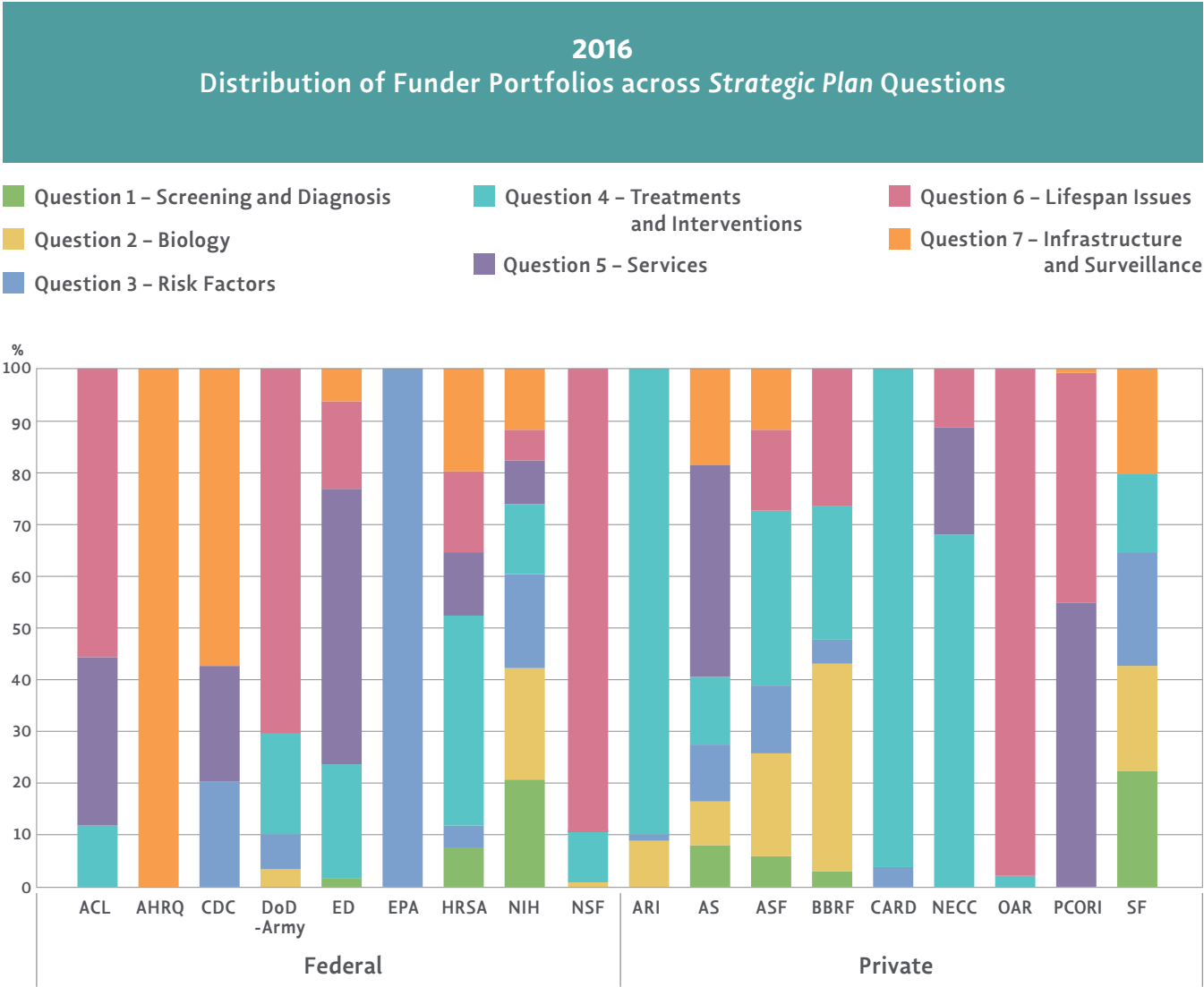


Figure 14. The portfolio of each federal agency and private organizations' autism-related projects by *Strategic Plan* question for 2016. Please note that this figure is based on funding amount from 2016. Thus, while funders may support additional areas of research, that may not be reflected in this particular year.

How did the research projects funded in 2016 align with the objectives in the IACC Strategic Plan?

The 23 IACC *Strategic Plan* objectives were developed by the IACC to set priorities for investment, and they represent areas where the Committee perceived gaps in research that required increased efforts. All autism research-related projects in 2016 were matched with the best fitting question and research objective in the *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 assigned to “Core/Other” rather than to a specific objective. The Core/Other category captures projects that may be related to cross-cutting or “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 2016 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 15**). In 2016, 4% of the funding went to projects that were designated as Core/Other. This was a significant decrease from 2015 (25%) and the previous years, due in large part to the new *Strategic Plan* objectives. The restructuring of the *Strategic Plan* objectives to have broader and more current research aims allowed many of the 2016 ASD research projects to fit more appropriately into specific objectives. However, each question area did still have a slight portion of its funding assigned to Core/Other (**Figure 16**).

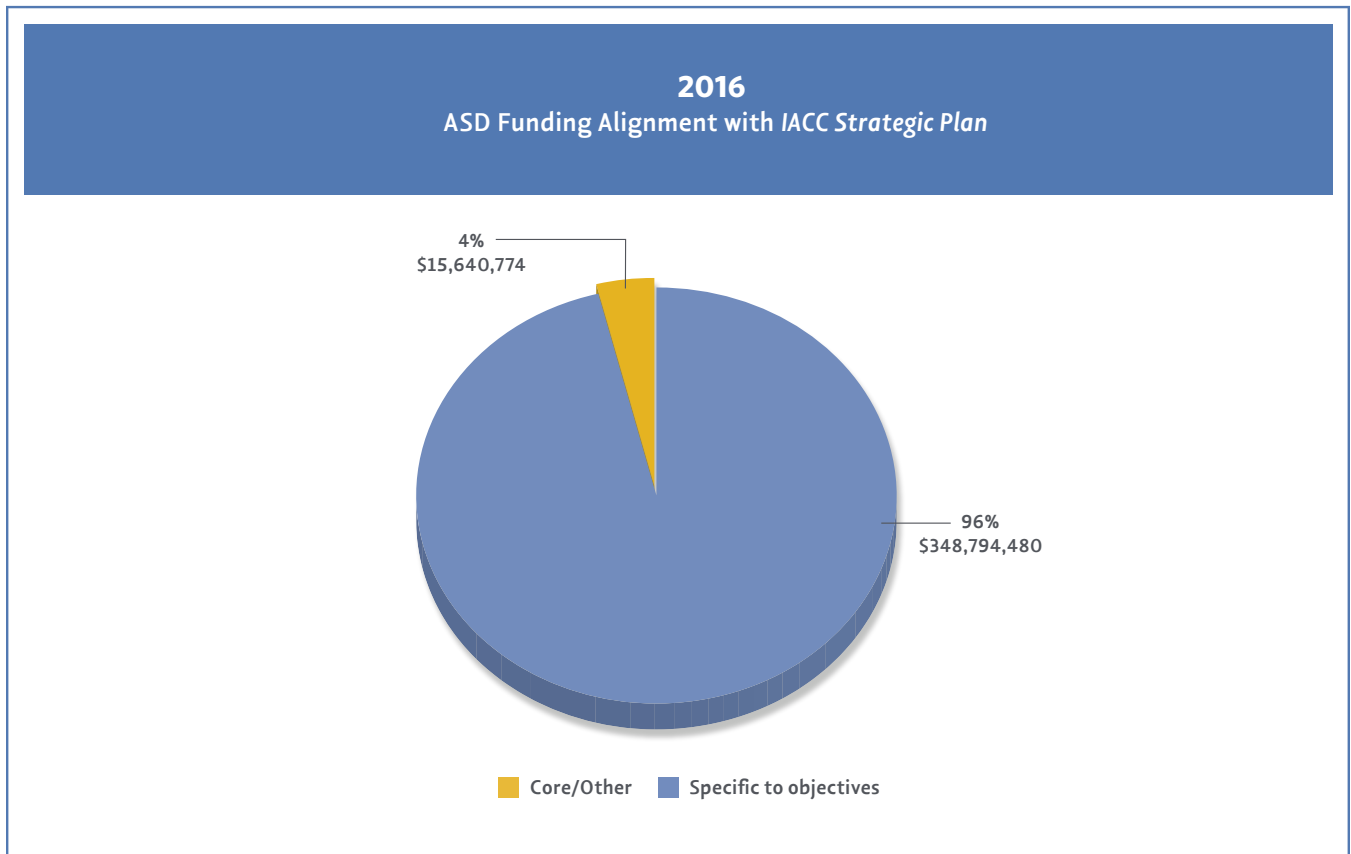


Figure 15. In 2016, 4% of funding went to projects that were not specific to a particular *Strategic Plan* objective, and were designated Core/Other.

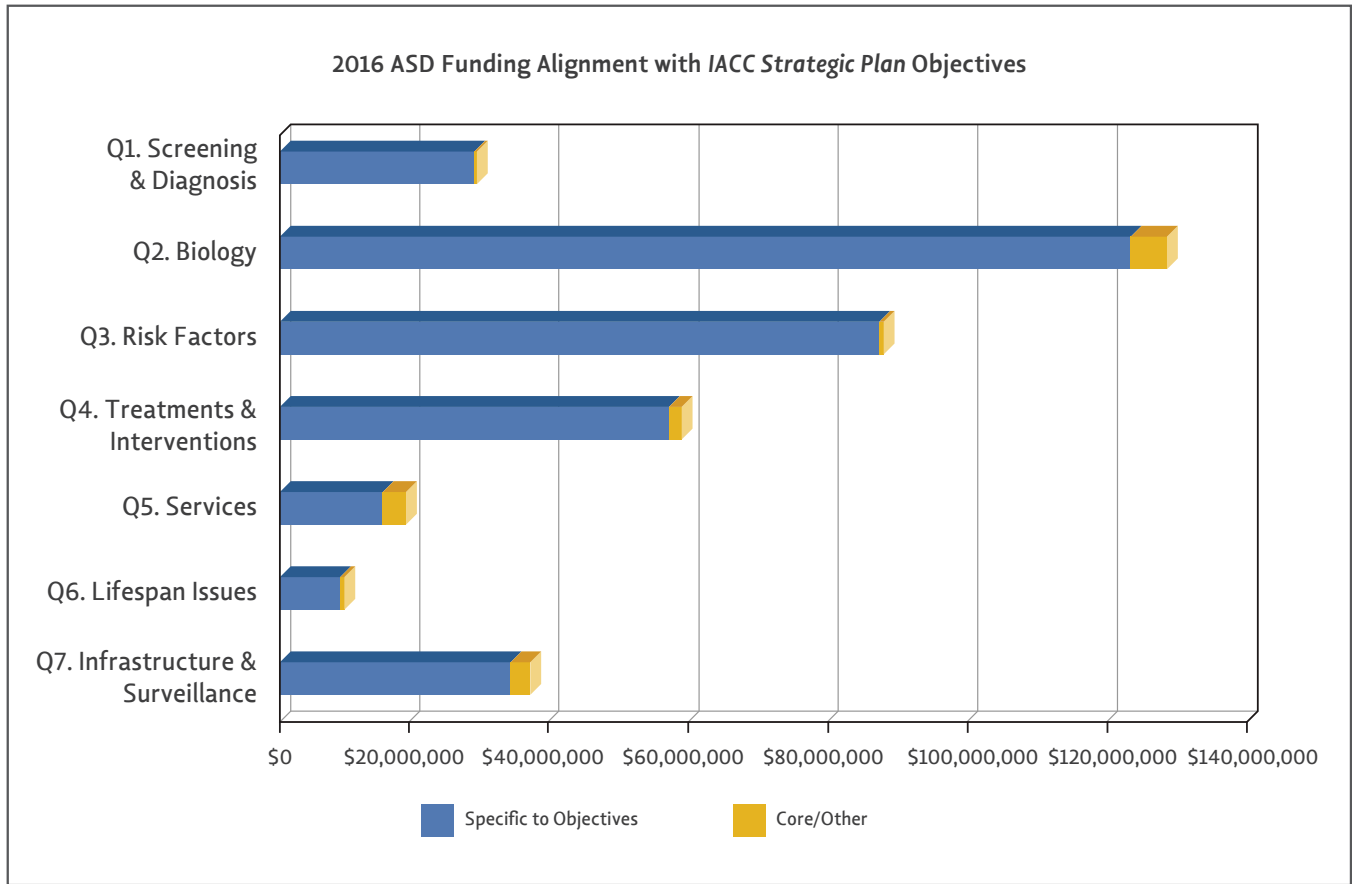


Figure 16. In 2016, the majority of funding for ASD projects was assigned to a specific objective within the *IACC Strategic Plan* questions. However, each question in the *Strategic Plan* contained projects that were not specific to a particular objective, designated Core/Other. Funding for projects that fall under specific objectives are indicated in blue, and Core/Other projects are indicated in yellow. Subcategory analysis provided within the summary 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 Progress 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 2016 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 aligned with the *IACC Strategic Plan* objectives yielded information about the progress that has been made towards the objectives in the *2016-2017 IACC Strategic Plan*. This 2016 portfolio analysis was the first to observe research progress towards the

new objectives; further discussion of the 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 progress in 2016 on funding objectives in each question, analysis of subcategories for each question, and a review of the overall trend in funding per each question of the *Strategic Plan*.

ANALYSIS OF PROGRESS TOWARD
IACC STRATEGIC PLAN OBJECTIVES
BY RESEARCH AREA

ANALYSIS OF 2016 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 8% (\$28 million) of the total ASD research in 2016. A total of 107 projects were assigned to Question 1, which was 8% of all projects. The largest funders of research pertaining to Question 1 in 2016 were the NIH, SF and HRSA. With the new *Strategic Plan*, progress made on Question 1 is measured through three primary objectives and one cross-cutting objective. **Figure 17** provides a detailed overview of each objective’s total funding in 2016 as well as the number of projects assigned to each objective.

In 2016, 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 71% (\$19.9 million) of the Question 1 funding

and consisted of majority of the Question 1 projects (82 projects). This was followed by objective 1.2, which focuses on reducing disparities in early detection and access to services. Objective 1.2 accounted for 24% (\$6.7 million) of Question 1 funding and included 16 projects. Objective 1.1 received 4% (\$1.1 million) of Question 1 funding and had 5 projects; the goal of this objective is to strengthen the evidence base for the benefits of early detection of ASD. Only 1% of Question 1 funding went to projects categorized as Core/Other, these are projects not specific to Question 1 objectives. Projects assigned to Core/Other included research on new technologies assessing early signs in visual and motor functioning and research on the development of symptoms associated with social and vocal engagement. 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 2016.

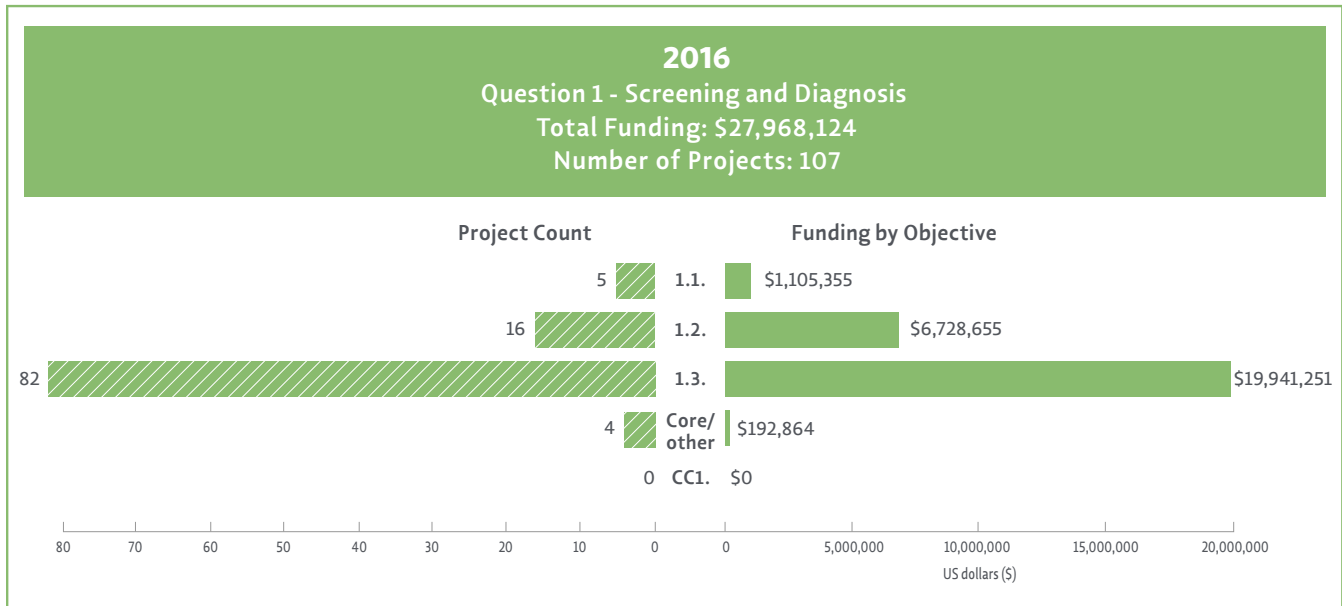


Figure 17. 2016 funding and project count by Question 1 objectives.

QUESTION 1 SUBCATEGORY ANALYSIS

With the development of the subcategory categorization scheme for the *IACC ASD Research Portfolio Analysis*, all projects can be 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 more 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** (Figure 18).

Of these four subcategories, the largest proportion of 2016 funding was devoted to the development of **Diagnostic and screening tools** for ASD (49%). Identifying **Early signs and biomarkers** was the second largest research investment in Question 1 (28%). 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. This was followed by research on identifying/characterizing **Intermediate phenotypes/Subgroups** of people with ASD (15%). The subcategory receiving the lowest proportion of funding included research characterizing **Symptomology** (8%).

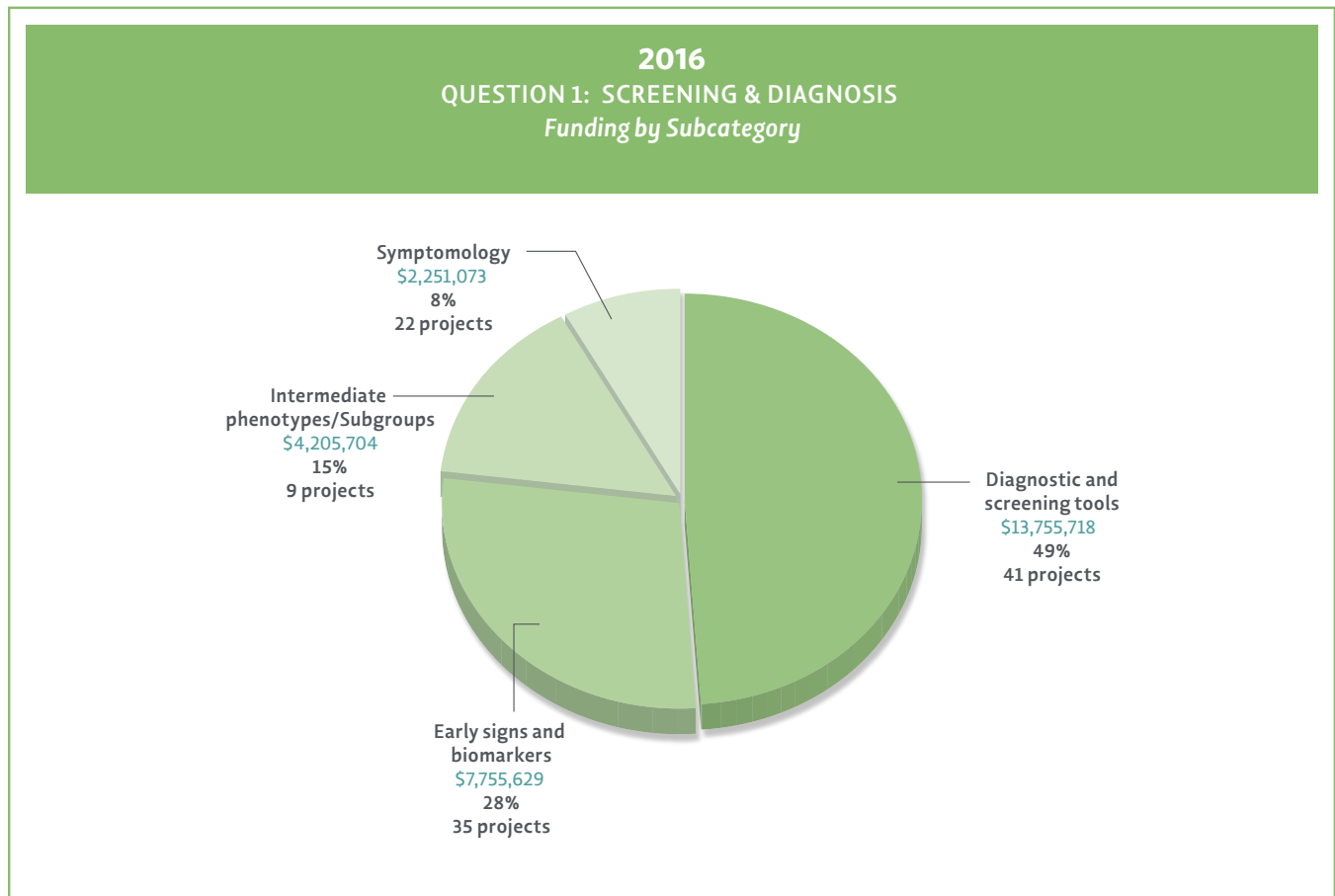


Figure 18. Question 1 funding by subcategory in 2016.

PROGRESS MADE ON QUESTION 1 FROM 2008-2016

Figure 19 shows the trend in Question 1 funding over time. When considering annual funding for Question 1 from 2008-2016, 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.

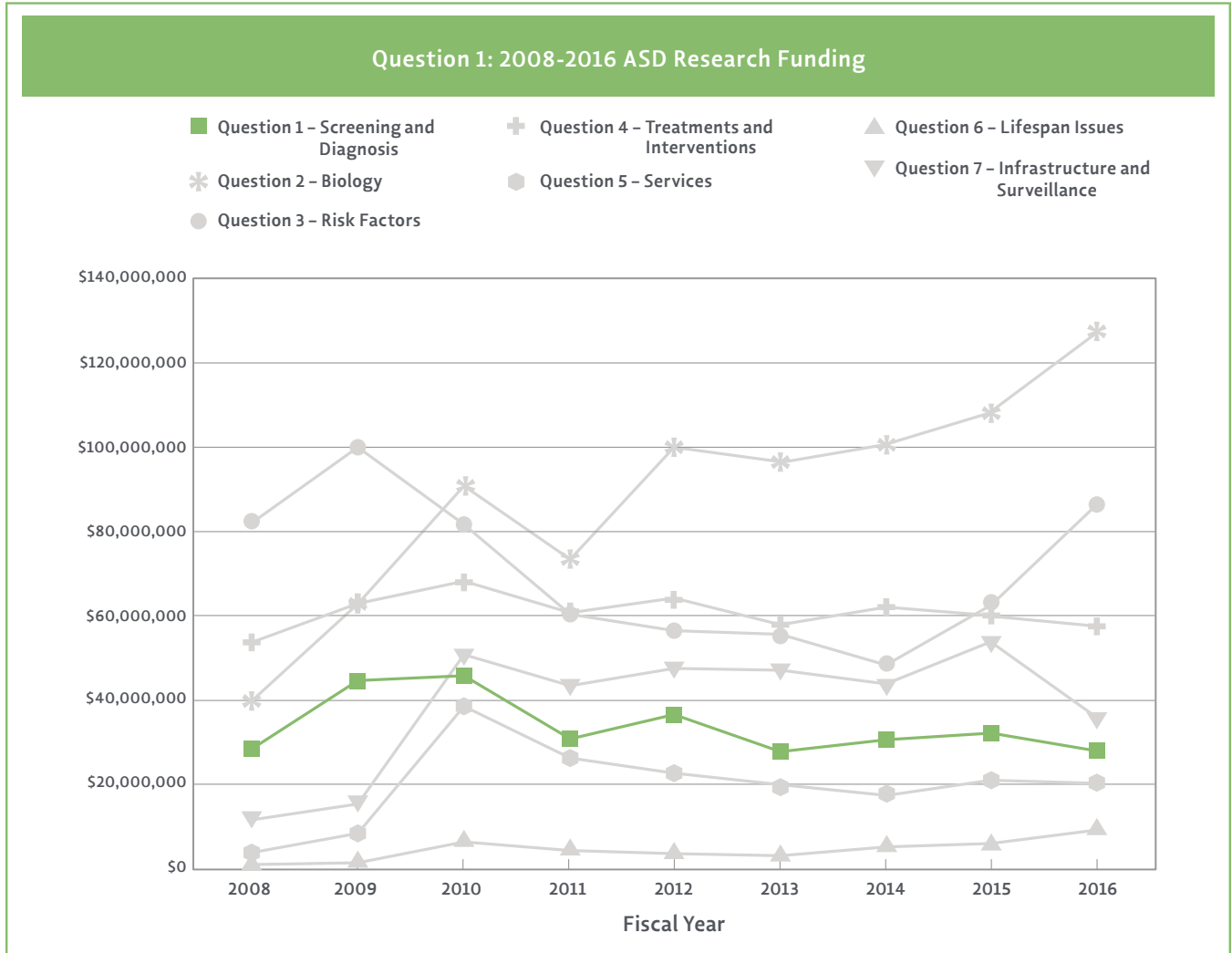


Figure 19. Question 1 ASD research funding from 2008-2016. Funding for Question 1 was moderate and stayed relatively flat over the nine-year span.



QUESTION 2 UNDERLYING BIOLOGY

ASPIRATIONAL GOAL: DISCOVER HOW ALTERATIONS IN BRAIN DEVELOPMENT AND THE FUNCTION OF PHYSIOLOGICAL SYSTEMS LEAD TO ASD IN ORDER TO ENABLE THE DEVELOPMENT OF EFFECTIVE, TARGETED INTERVENTIONS AND SOCIETAL ACCOMMODATIONS THAT IMPROVE QUALITY OF LIFE FOR PEOPLE ON THE AUTISM SPECTRUM.

RESEARCH FOCUS OF QUESTION 2

Question 2 (“What is the biology underlying ASD?”) seeks to understand the biological differences and mechanisms in early development and throughout life that contribute to ASD symptoms, as well as the characterization of the behavioral and cognitive aspects of ASD. The aim of the research represented by Question 2 is to understand the biological processes underlying ASD from the molecular level to sensory, motor, behavioral, and cognitive development and functioning. Projects range from basic neuroscience using cellular and animal models to clinical studies.

A word cloud was created using the project titles listed under Question 2 to provide a visual representation of the research funded in 2016 (depicted above). The size of each word within the word cloud indicates the frequency of its use in project titles. The word cloud visually depicts the main research themes and topics that were associated with projects categorized under Question 2.

ANALYSIS OF 2016 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 2016. Following similar trends as previous years, research on the biology of ASD (Question 2) comprised 35% of total funding (\$127.4 million). Question 2 also had the largest portion of overall projects in 2016 (36%, 491 projects). Among federal agencies and private organizations, the National Institutes of Health provided the largest investment, contributing 89% of total Question 2 research funding. The Simons Foundation was the next largest funder for Question 2. Research funding under Question 2 is categorized under three primary objectives and one cross-cutting objective. **Figure 20** provides a detailed overview of each objective's total funding in 2016 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 2016. The majority of projects were categorized under objective 2.1, with 75% of Question 2 funding (\$96 million). 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 (10% of funding; \$12.9 million), which focuses on supporting large-scale longitudinal studies that assess the natural lifespan of ASD. Objective 2.2, which emphasizes research in understanding co-occurring conditions, received \$8.4 million and accounted for 7% of Question 2 funding. The cross-cutting objective (CC1) received 4% of funding (\$4.9 million) in 2016 under Question 2. 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 significant portion of its funding designated to Core/Other. In 2016, only 4% (\$5.1 million) of Question 2 funding was assigned to Core/Other. Projects assigned to Core/Other included research studying the communicative behaviors of non-human primate models and the behavioral effects of fever on young children with autism. With the revision of the *Strategic Plan*, projects under Question 2 are now more aligned with the new objectives.

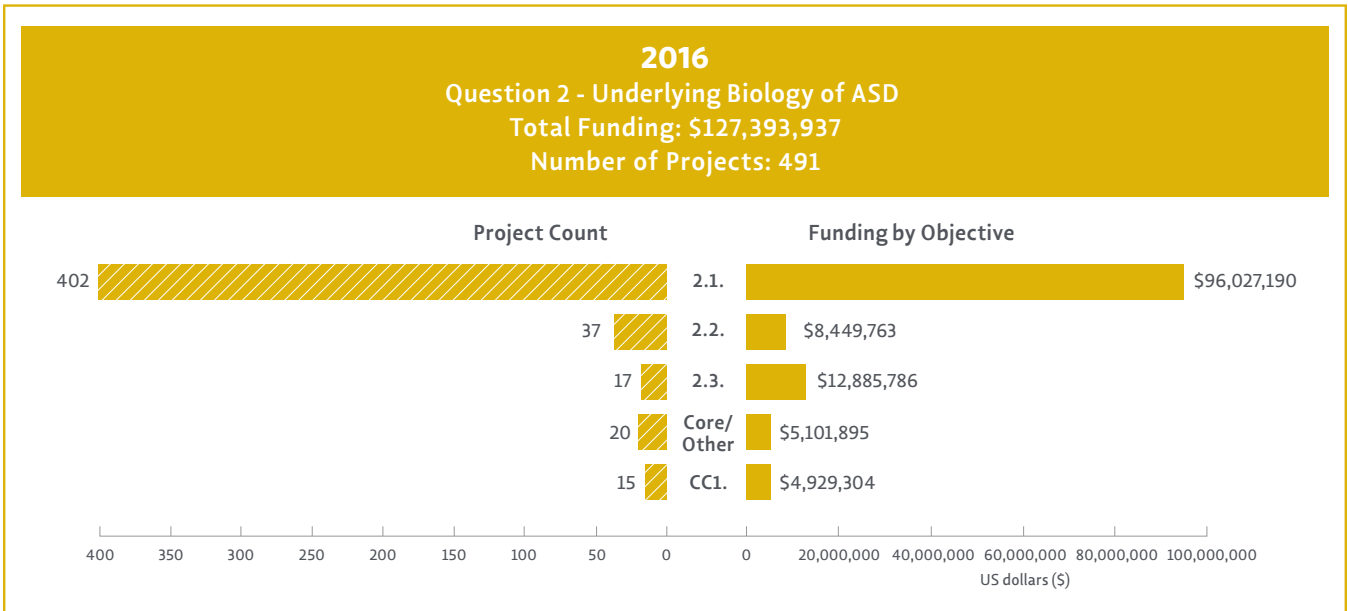


Figure 20. 2016 funding and project count by Question 2 objectives.

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** (Figure 21).

As in previous years, the Question 2 subcategory with the largest portion of funding was **Molecular pathways** (33%), which includes projects seeking to understand systems of genes, proteins, and other molecules that are involved in ASD and related disorders. Research

exploring the **Neural systems**, such as the structure of the brain and functional connections within the brain, was the second largest investment (20%). Research into the **Developmental trajectory** of ASD, including longitudinal studies that follow social, behavioral, and physical development over time accounted for 12% of Question 2 funding in 2016. The next largest subcategory focused on projects aiming to identify **Subgroups/Biosignatures** of ASD (9%). **Cognitive studies** accounted for 6% of ASD funding in 2016. Research investigating **Sensory and motor function** as well as the **Neuropathology** of ASD each accounted for 5% of Question 2 funding. Projects examining **Immune/Metabolic pathways** and **Co-occurring conditions** each received 4% of funding. Lastly, research in **Computational science** accounted for 2% of Question 2 funding in 2016.

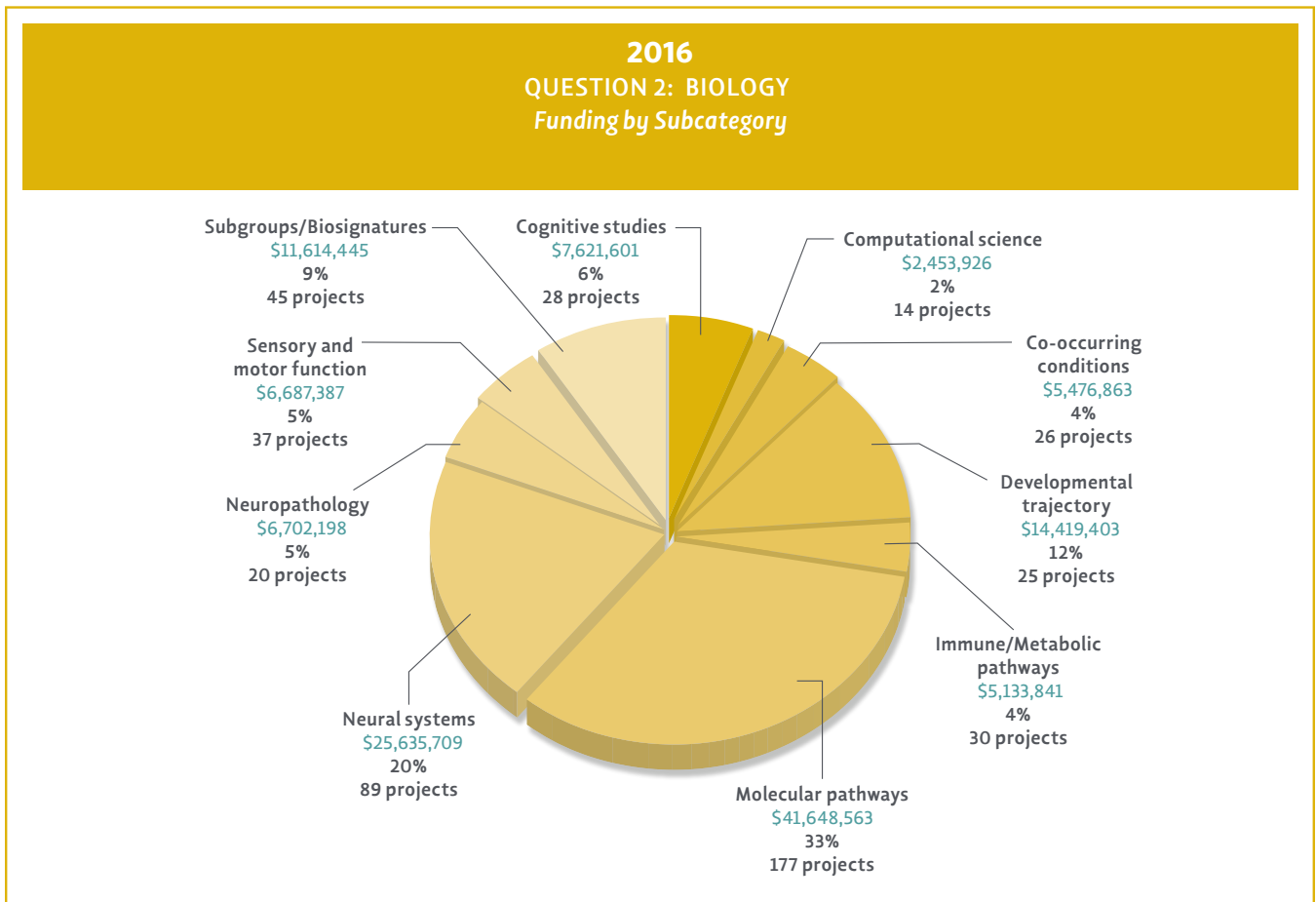


Figure 21. Question 2 funding by subcategory in 2016.

PROGRESS MADE ON QUESTION 2 FROM 2008-2016

Figure 22 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 2008-2016, funding levels for this question increased significantly in recent years. It is important to note that the new 2016-2017 Strategic Plan objectives have 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 substantial increase between 2015 and 2016. However, Question 2 is the only question area that has seen a significant increase in funding over the period from 2008-2016. Most of the other research areas remained relatively flat or decreased.

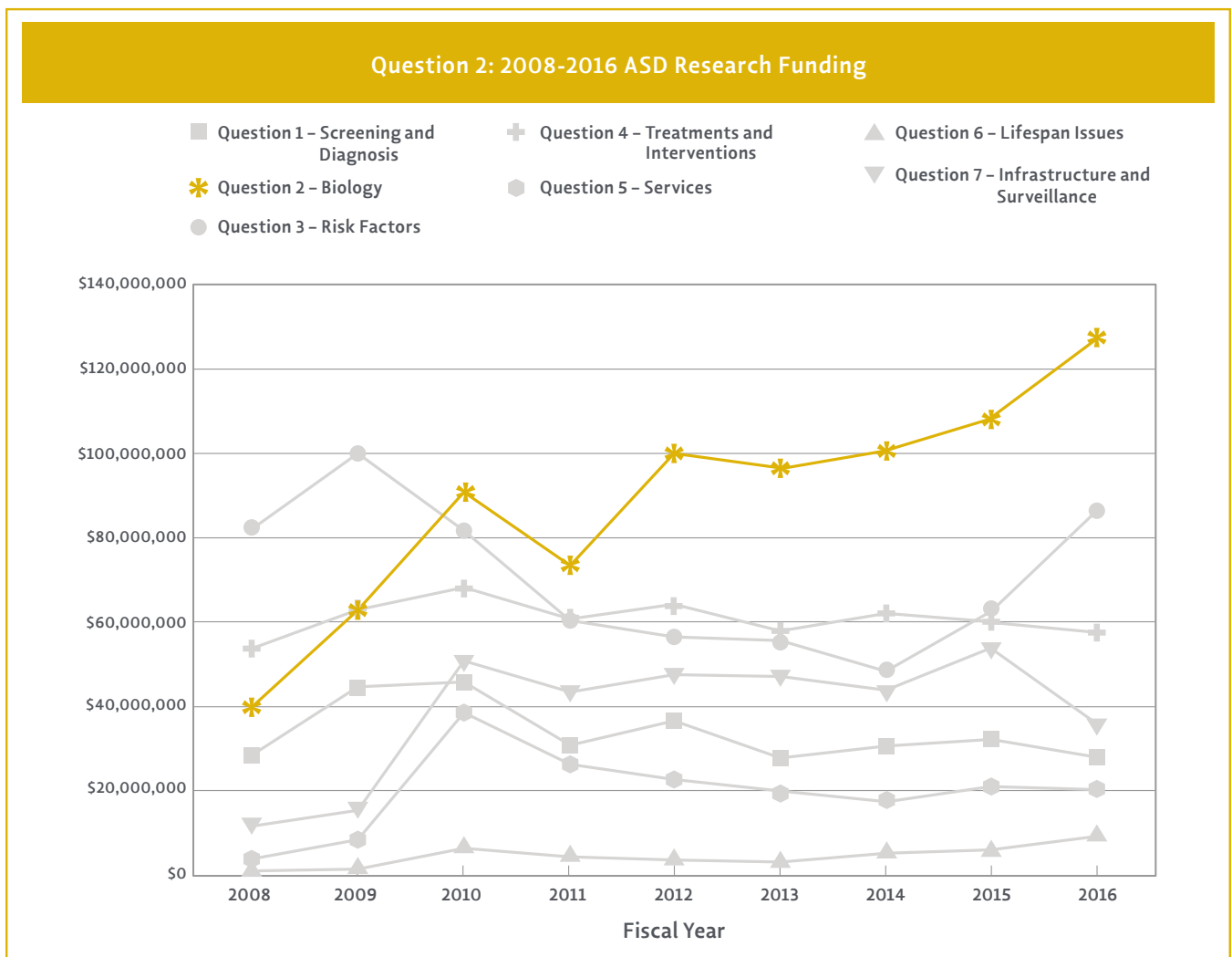


Figure 22. Question 2 ASD research funding from 2008-2016. Funding for Question 2 has experienced several substantial increases in funding over the nine-year span, leading to a continual upward trend.

ANALYSIS OF 2016 QUESTION 3 PORTFOLIO

In 2016, research on risk factors associated with ASD (Question 3) accounted for \$86.5 million (24%) of total ASD research funding. A total of 240 projects were assigned to Question 3, which was 18% of all projects in the 2016 ASD portfolio. The largest funders of Question 3 are the National Institutes of Health, Simons Foundation, and Centers for Disease Control and Prevention. Question 3 consists of three primary objectives and the cross-cutting objective. **Figure 23** provide a detailed overview of each objective’s total funding in 2016 as well as the number of projects assigned to each objective.

Each Question 3 objective received funding in 2016. Objective 3.1 received the largest proportion of funding,

which identifies and strengthens the understanding of genetic risk factors for ASD (\$52.6 million; 61% of Question 3 funding). This was followed by objective 3.3, which supports projects studying environmental and genetic exposures (\$18.7 million, 22%). Objective 3.2 focuses on environmental risk factors associated with ASD and it received \$14.4 million and accounted for 17% of Question 3 funding. The cross-cutting objective (CC1) for Question 3, which investigates the genetic and/or environmental risk associated with sex differences in ASD, had four projects and received \$0.2 million (<1%). Question 3 Core/Other had one project that accounted for \$0.5 million and 1% of funding, this project is studying the genetic associations in brain development within autism.

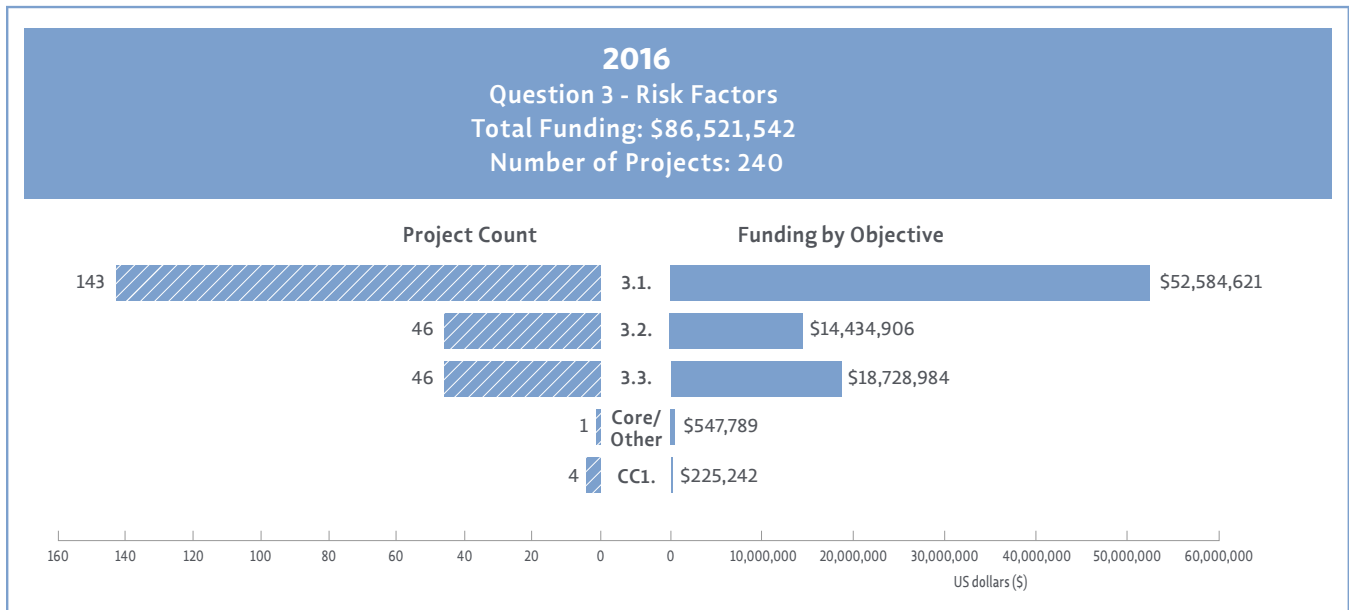


Figure 23. 2016 funding and project count by Question 3 objectives.

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 risk factors for ASD. These subcategories include: **Environmental risk factors; Epigenetics; Gene-Environment studies; and Genetic risk factors (Figure 24).**

In 2016, studies focused on **Genetic risk factors** accounted for the highest percentage of Question 3 funding (58%). Genetic risk factors experienced a large increase in funding from 2015 (38%) to 2016 which is attributable to the new *Strategic Plan* objectives. Particularly, the Simons Foundation's **SPARK** research

projects was reassigned from Question 2 to Question 3 based on the project's research aims focused on advancing our understanding of genetic information. The SPARK multisite project is a large research initiative that added a significant portion of funding to Question 3. The next largest Question 3 subcategory investigates the role of environmental risk factors, genetic susceptibility, and/or the context of human physiology (**Gene-Environment; 22%**). Projects considering only **Environmental risk factors** received 14% of Question 3 funding. Projects on **Epigenetics** received 6% of funding, which included studies investigating DNA modifications and exploring altered gene expression due to environmental influences.

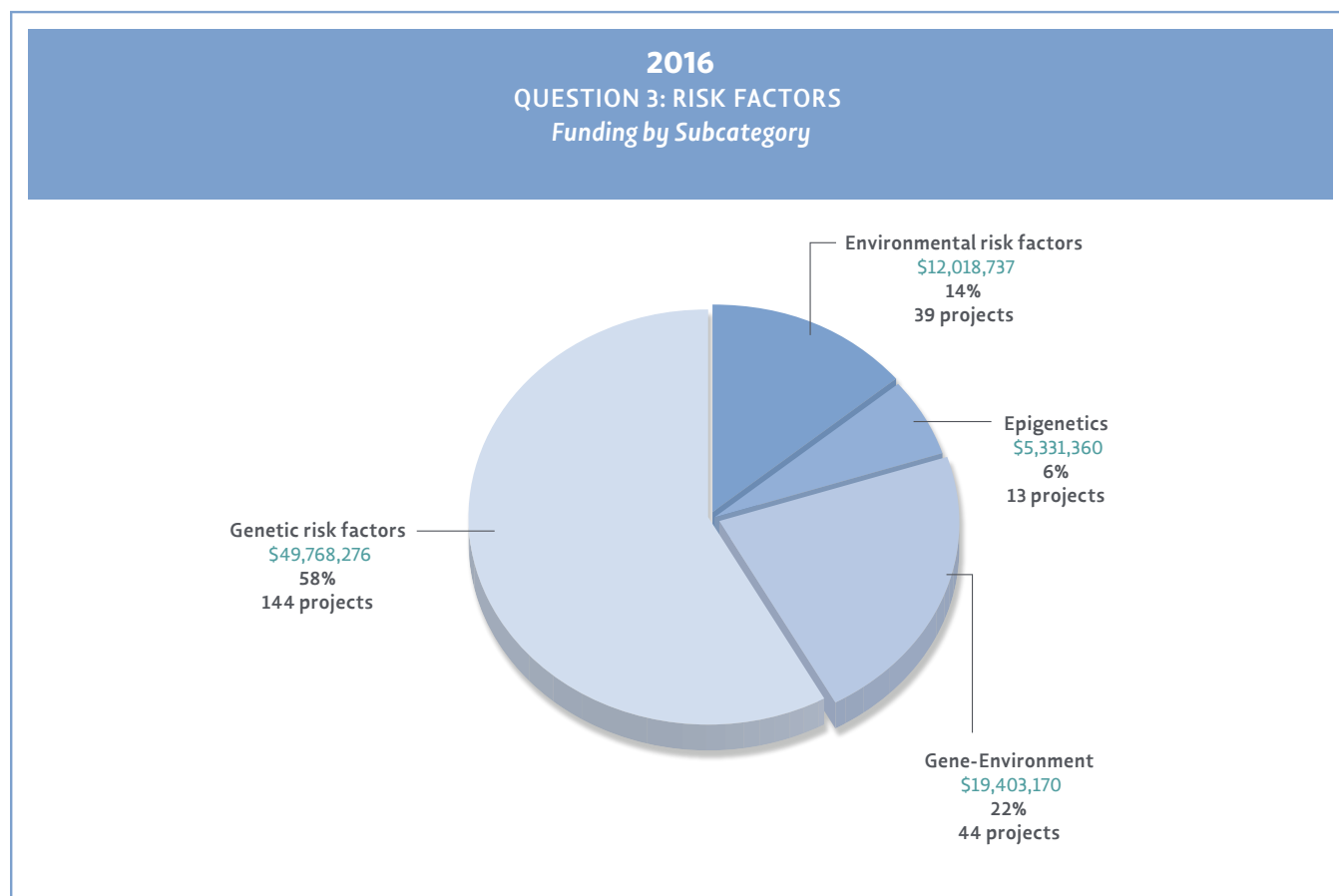


Figure 24. Question 3 funding by subcategory in 2016.

PROGRESS MADE ON QUESTION 3 FROM 2008-2016

Figure 25 shows the trend in Question 3 funding over time. While research on risk factors remained supported at high levels over the nine-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.

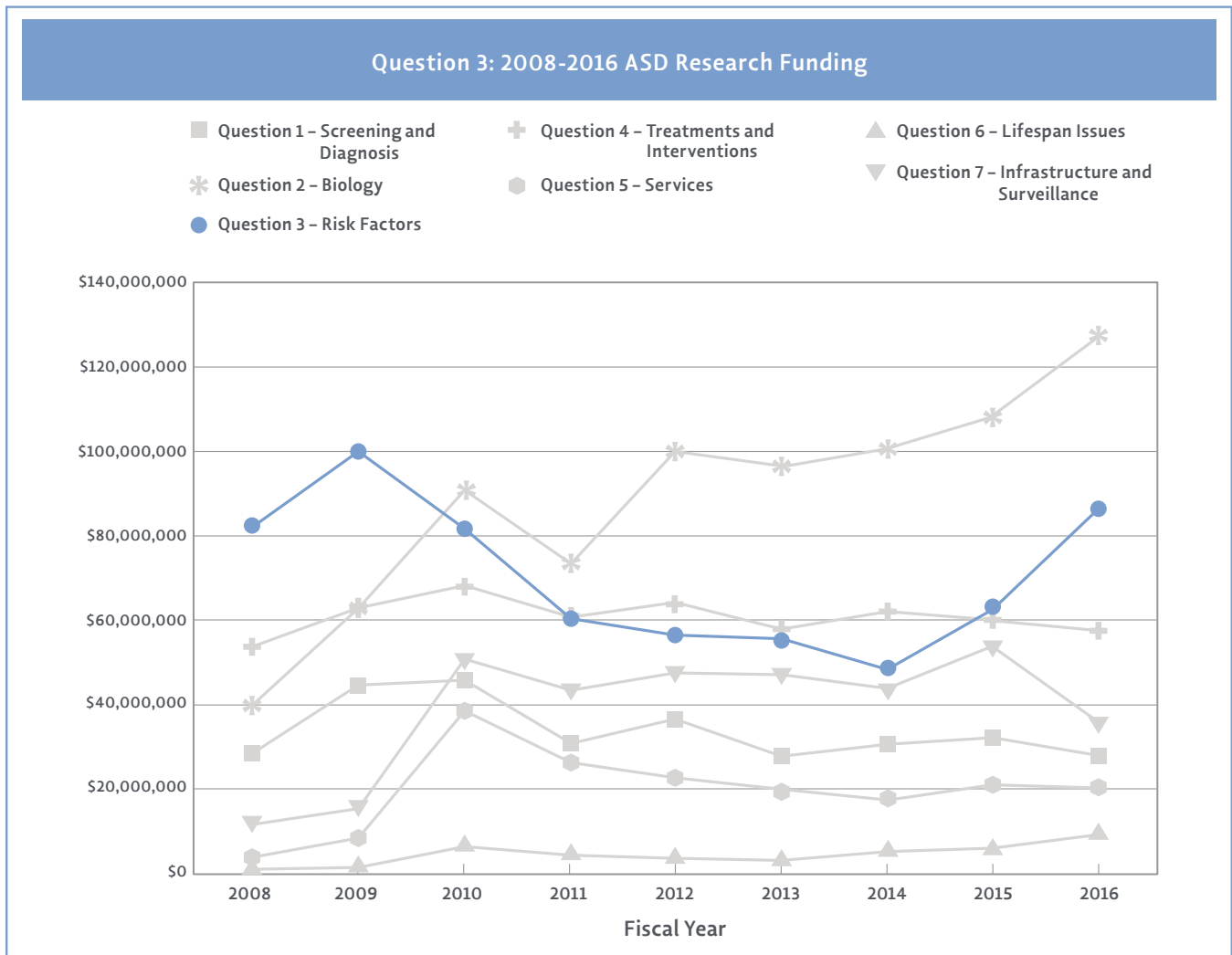


Figure 25. Question 3 ASD research funding from 2008-2016. Over the nine-year span, funding for Question 3 initially showed an increase followed by a sharp decrease, then a gradual decrease, and finally a rapid increase from 2014-2016.

ANALYSIS OF 2016 QUESTION 4 PORTFOLIO

Research focused on interventions and treatments received \$57.8 million (16%) of total ASD funding in 2016. The number of projects assigned to Question 4 totaled 254 projects, which was 19% of all projects included in the portfolio. A large number of agencies and organizations invest in treatments and interventions; however, the three largest funders are the National Institutes of Health, Department of Education, and Health Research and Services Administration. Question 4 has three primary objectives and the cross-cutting objective. **Figure 26** provides a detailed overview of each objective’s total funding and the number of projects assigned to each objective in 2016.

Every objective in Question 4 as well as the cross-cutting objective had assigned projects and funding in 2016. The Question 4 objective receiving the most funding, objective 4.2, focuses on the development of psychosocial and naturalistic interventions (\$24.2

million, 42%), this objective also had the largest number of projects (118 projects). The second largest funded objective was objective 4.1 with \$23.6 million (42%; 70 projects), which includes research on pharmacological and medical interventions. Objective 4.3 followed, with the goal to optimize development of technology-based interventions, it received \$7.9 million (14%) and had 54 projects. 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 the differences. In 2016, there was one project associated with the cross-cutting objective which totaled \$35,000. The rest of Question 4 funding went to projects categorized as Core/Other, which accounted for \$2.1 million and 11 projects (3%). Projects assigned to Core/Other included parent training interventions and assessing brain imaging markers in response to interventions in toddlers with autism.

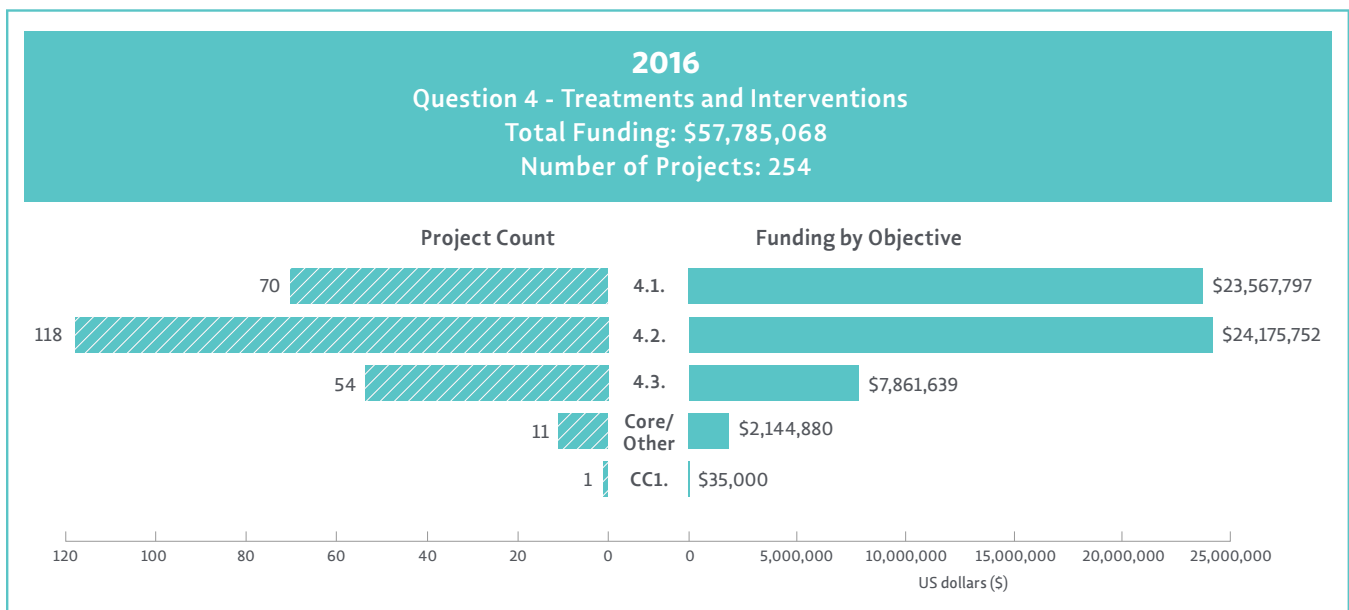


Figure 26. 2016 funding and project count by Question 4 objectives.

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 symptoms, to behavioral therapies and technologies to improve communication, socialization, 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** (Figure 27).

The subcategories for Question 4 (Treatments and Interventions) illustrate the many approaches to treatments and interventions supported by autism research funders. In 2016, the largest amount of funding supported projects to develop **Behavioral** interventions (31%), including applied behavior analysis (ABA), cognitive therapy, and social skills training. Research on **Model systems/Therapeutic targets** (22%) followed, focusing on early development of

animal and cellular models that mimic characteristics of ASD to test experimental therapies. The **Model systems/Therapeutic targets** subcategory experienced a decrease in funding and projects from 2015 to 2016. Due to the new objectives in the *2016-2017 Strategic Plan*, objectives experienced a shift in the categorization of some projects using ASD model systems. Among the model systems projects, which formerly were all assigned to Question 4, under the *2016-2017 Strategic Plan*, some of these projects are now better suited under Question 2 while those specifically focused in testing new drugs and treatments remain in Question 4. The next largest subcategory in 2016 was **Medical/Pharmacologic** interventions, which received 17% of funding. **Technology-based interventions and supports** received 13% of funding and **Educational** (classroom-based) interventions received 11% of funding in 2016. The subcategories with the smallest amounts of funding included **Occupational, physical, and sensory-based** (5%) and **Complementary, dietary, and alternative interventions** (1%).

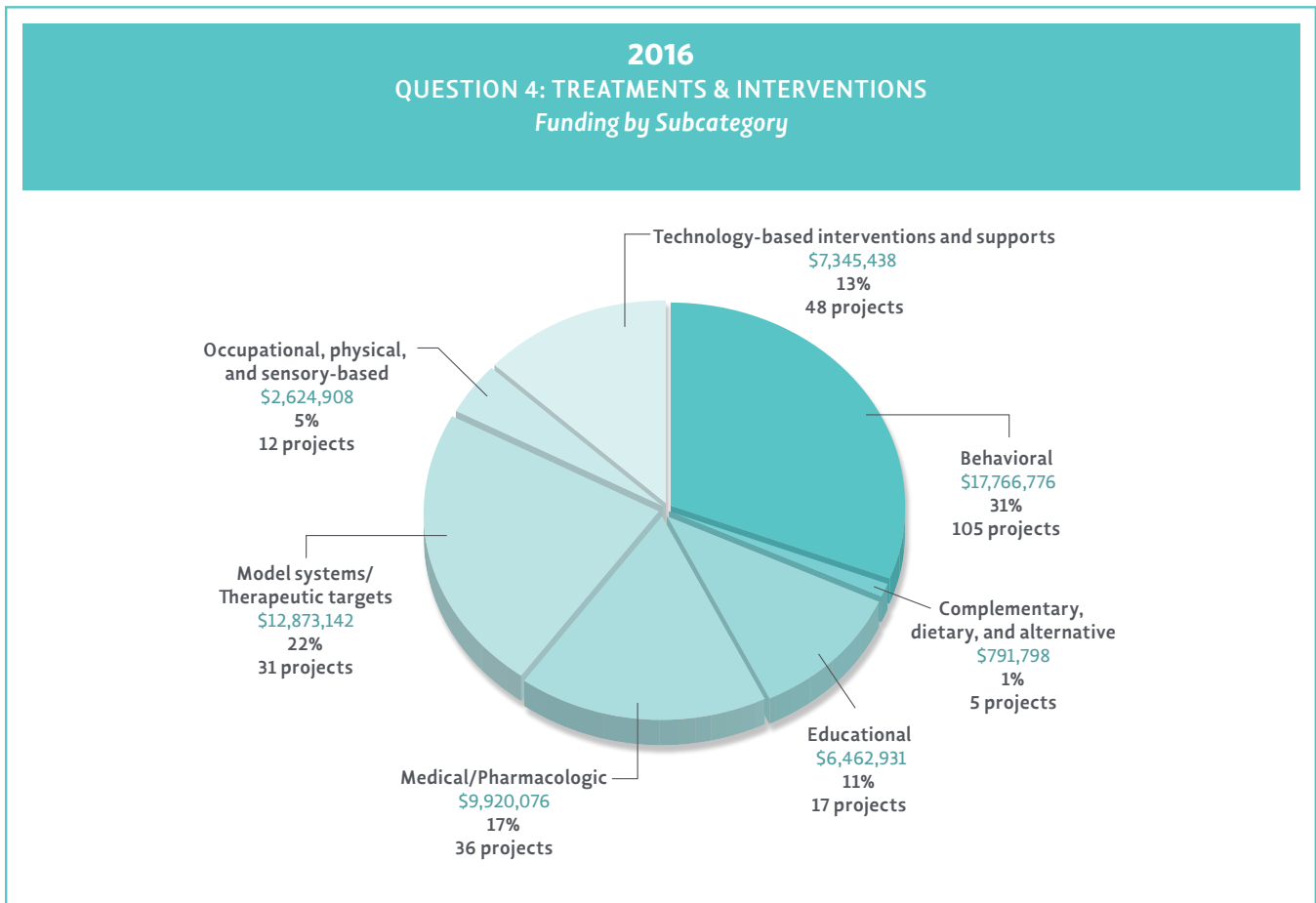


Figure 27. Question 4 funding by subcategory in 2016.

PROGRESS MADE ON QUESTION 4 FROM 2008-2016

The trend in annual Question 4 funding over time is shown in **Figure 28**. Overall, research funding focused on treatments and interventions maintained a steadily moderate level over the nine-year time span. In recent

years, Question 4 has seen a slight decline in funding; however Question 4 has consistently had one of the largest proportions of funding compared to other question areas.

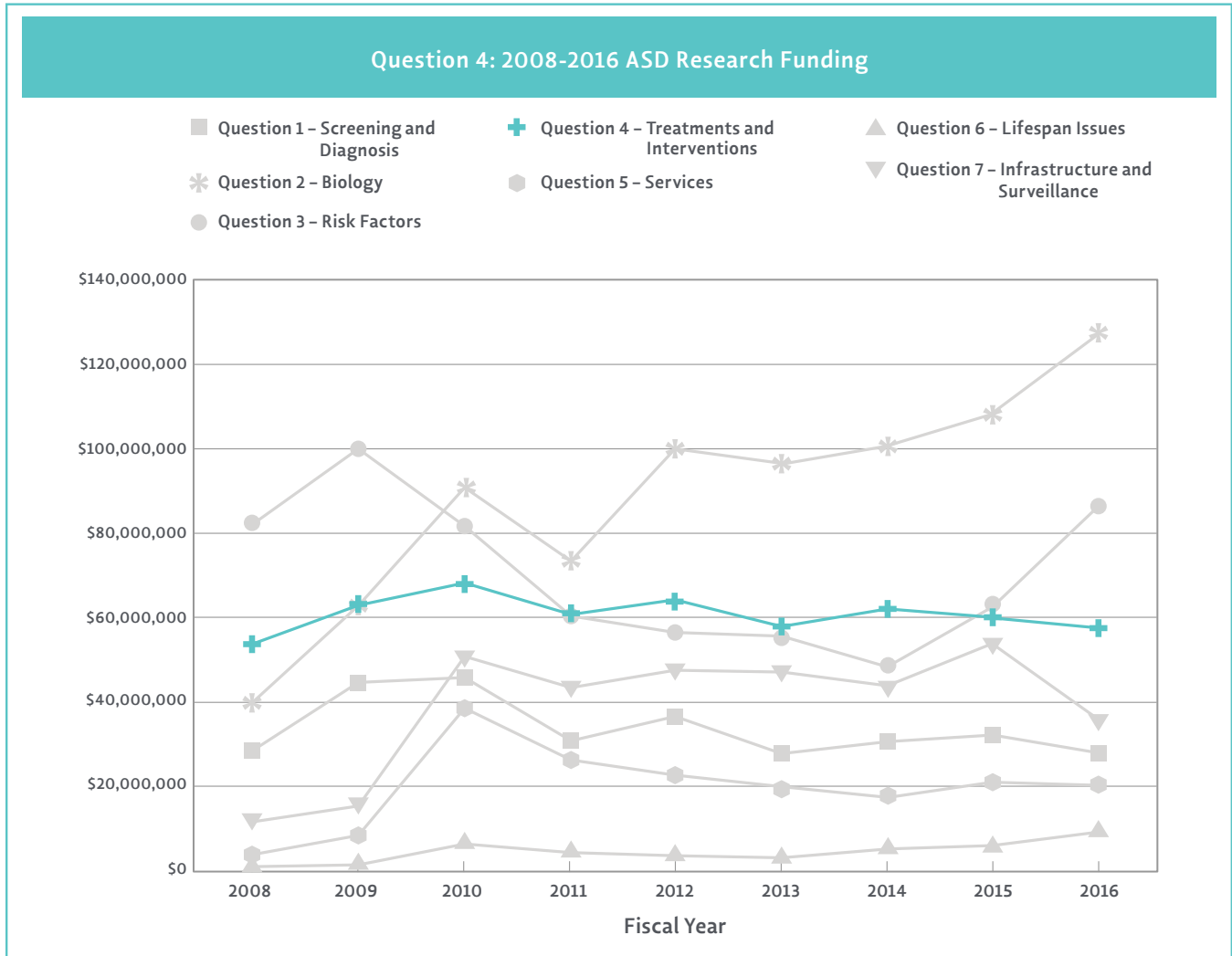


Figure 28. Question 4 ASD research funding from 2008-2016. Funding for Question 4 remained primarily flat, but relatively robust, over the nine-year span.

ANALYSIS OF 2016 QUESTION 5 PORTFOLIO

Projects assigned to Question 5 comprised 5% of the total ASD research supported in 2016 (\$19.6 million) and consisted of 84 projects, which was 6% of the total number of ASD projects. The largest funders of Question 5 are the Department of Education, National Institutes of Health, and Centers for Disease Control and Prevention. Question 5 consists of three primary objectives and a cross-cutting objective. **Figure 29** provides a detailed overview of each objective’s total funding in 2016 as well as the number of projects assigned to each objective.

All three primary objectives in Question 5 received funding in 2016. The majority of projects that were categorized under this question went towards objective 5.1, which addresses the gaps between research and practice when implementing evidence-based practices within the community. Objective 5.1 was 40% of the Question 5 portfolio, receiving \$7.8 million in funding and included 19 projects. The next largest portion

of funding went to 5.3, which supports developing and improving service models to improve the quality of care individuals get from ASD services. This objective received \$7.5 million (38%) and had 39 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 (3 projects). Question 5 Core/ Other received 21% of Question 5 funding, with \$4.1 million and 23 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 research did not receive any Question 5 funding in 2016. Future projects that would potentially fit in the cross-cutting objective within Question 5 include differences in services and supports needs based on sex and gender.

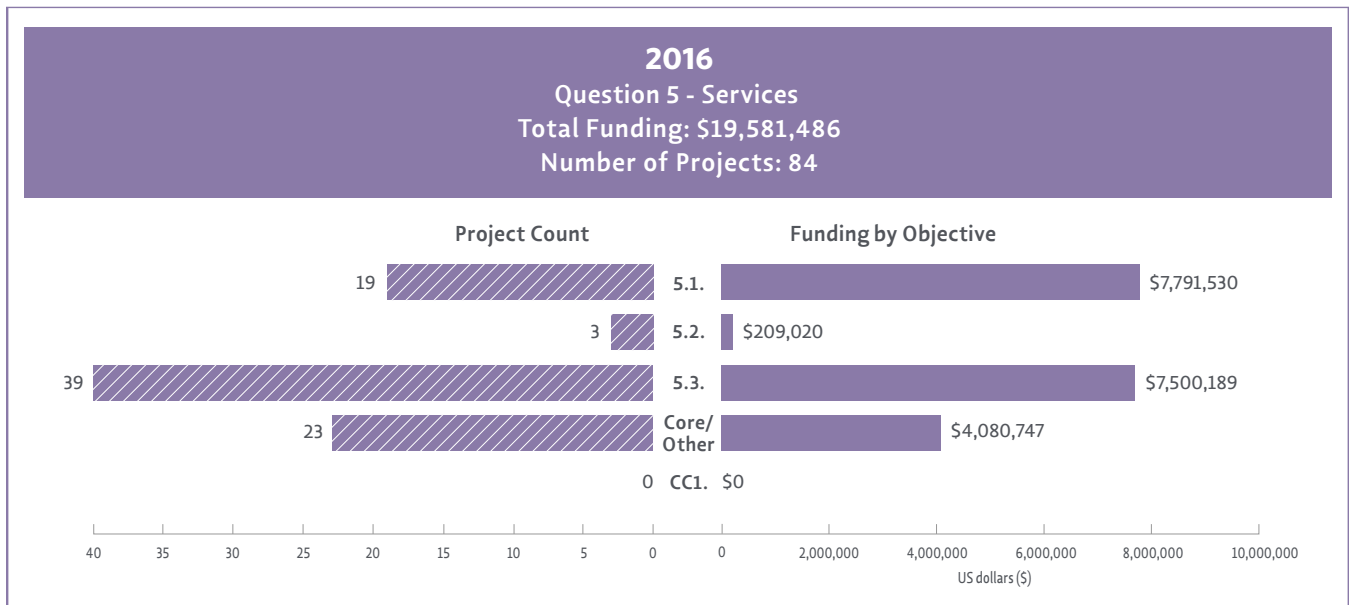


Figure 29. 2016 funding and project count by Question 5 objectives.

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 (Figure 30).**

In 2016, research concerning the development and evaluation of **Practitioner training** accounted for over half (55%) of Question 5 funding. Projects related to

research on **Efficacious and cost-effective service delivery**, which covers research projects that assess current service delivery models as well as developing new and efficient ways of providing services, followed with 33% of Question 5 funding. **Family well-being and safety** research projects followed with 7% of funding in 2016. Projects relating to **Community inclusion programs** received 3% of funding. Research focused on disparities and potential barriers to access are covered in **Services utilization and access** and accounted for 2% of Question 5 funding.

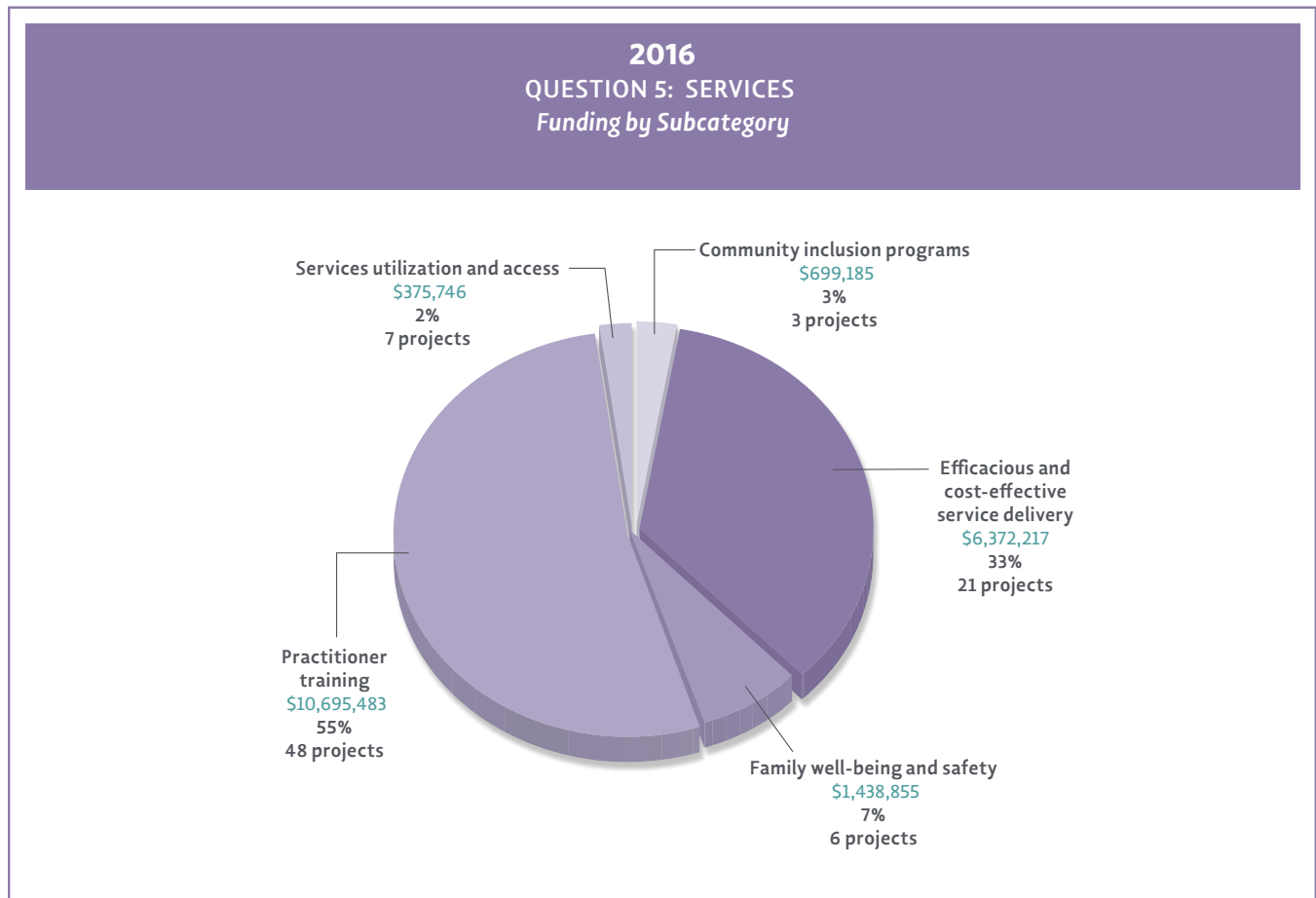


Figure 30. Question 5 funding by subcategory in 2016.

PROGRESS MADE ON QUESTION 5 FROM 2008-2016

Figure 31 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 slightly after 2010.¹ Overall, when comparing 2008 funding for Question 5 with 2016 funding the general trend is upward.

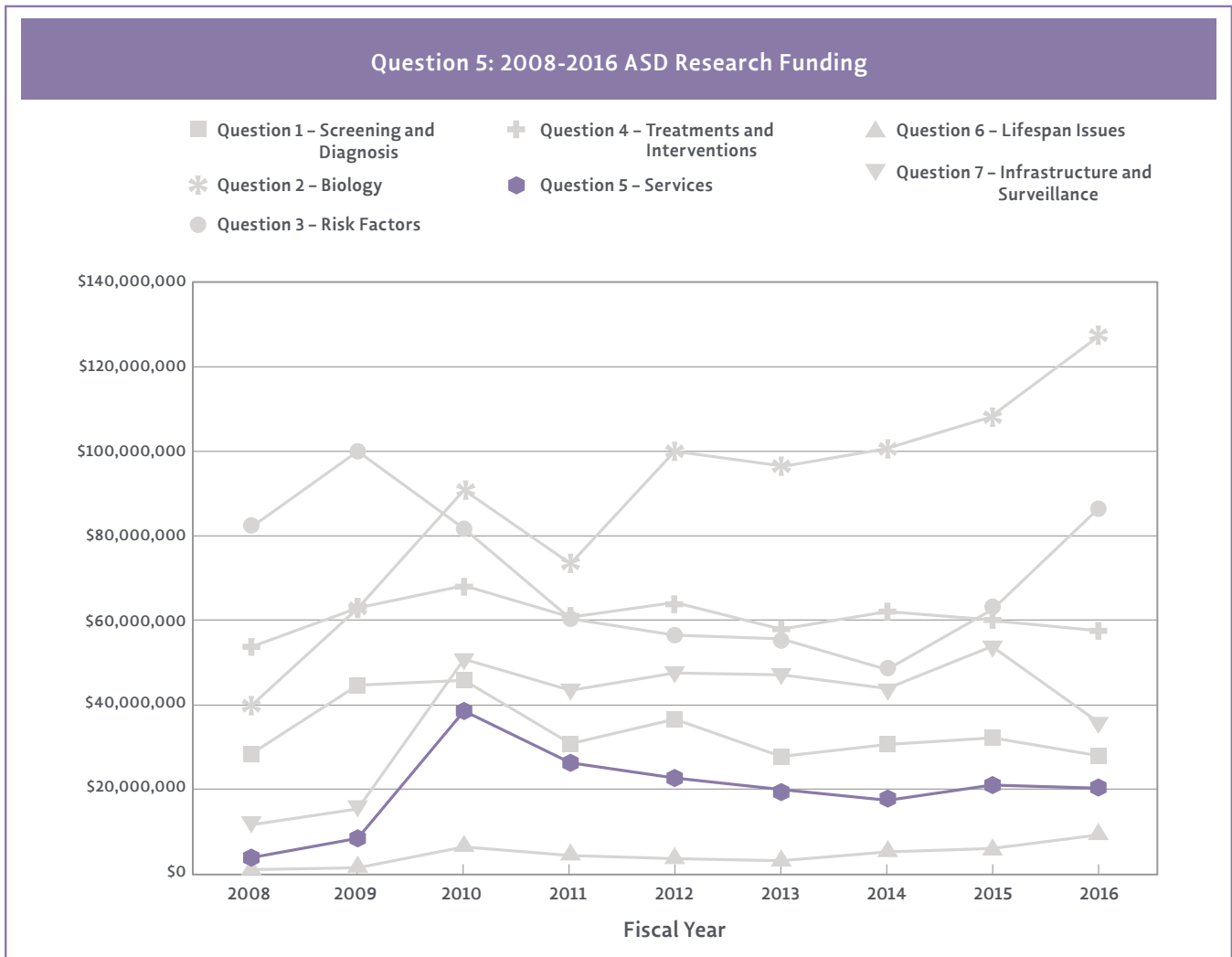


Figure 31. Question 5 ASD research funding from 2008-2016. Compared to other *Strategic Plan* questions, funding for Question 5 remained relatively low over the nine-year span.

¹As 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.



QUESTION 6 LIFESPAN ISSUES

ASPIRATIONAL GOAL: ALL PEOPLE WITH ASD WILL HAVE THE OPPORTUNITY TO LEAD SELF-DETERMINED LIVES IN THE COMMUNITY OF THEIR CHOICE THROUGH SCHOOL, WORK, COMMUNITY PARTICIPATION, SATISFYING RELATIONSHIPS, AND MEANINGFUL ACCESS TO SERVICES AND SUPPORTS.

RESEARCH FOCUS OF QUESTION 6

With increasing societal awareness of the needs of people on the autism spectrum across the lifespan, Question 6 addresses the question “How can we meet the needs of people with ASD as they progress into and through adulthood?”. Question 6 encompasses research to identify and address issues surrounding transitioning to adulthood, improving co-occurring physical and mental health conditions for adults, and incorporating acceptance and independence of people with ASD in services and outreach efforts. Some of the research in Question 6 represents projects that assess outcome measures such as quality of life, health, independence, and employment for people on the autism spectrum, particularly with respect to interventions and services they might have

received. Many projects assigned to Question 6 focus on adolescents transitioning from the secondary education system to higher education and/or employment, as well as vocational/job skills and social skills training for both transitional aged youth and adults.

In an effort to describe the research funded in Question 6 in 2016, a word cloud was created using the project titles listed under this question (depicted above). The size of each word within the word cloud indicates the frequency of its use in project titles. The word cloud visually portrays the main research themes and topics that were associated with projects categorized under Question 6.

ANALYSIS OF 2016 QUESTION 6 PORTFOLIO

In 2016, research on lifespan issues associated with ASD (Question 6) accounted for 2% (\$9.1 million) of total ASD research funding and included 48 projects. This question area had the smallest portion of funding and number of projects. The agencies and organizations with the largest stakes in this research are the National Science Foundation, National Institutes of Health, and the Department of Defense (Army). Question 6 has three primary objectives and the cross-cutting objective. **Figure 32** provides a detailed overview of each objective’s total funding as well as the number of projects assigned to each objective.

All three primary objectives assigned to Question 6 received funding. The largest portion of funding went to research supporting the transition to adulthood; objective 6.1 accounted for nearly three-quarters of Question 6 funding (74%) which totaled \$6.7 million

and 24 projects. Research focused on community integration, objective 6.3, followed with \$1.2 million (14%) and 16 projects. Objective 6.2 received \$0.6 million (6%) and included 3 projects; the goal of this objective is to conduct research to enhance quality of life and reduce the disabling effects of co-occurring conditions. Question 6 Core/Other accounted for 6% of funding, with \$0.6 million and 5 projects. Projects assigned to Core/Other included studying 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, did not receive funding in 2016. Future projects associated with the cross-cutting objective in Question 6 might include understanding the sex differences in adults and how it might affect health and life outcomes.

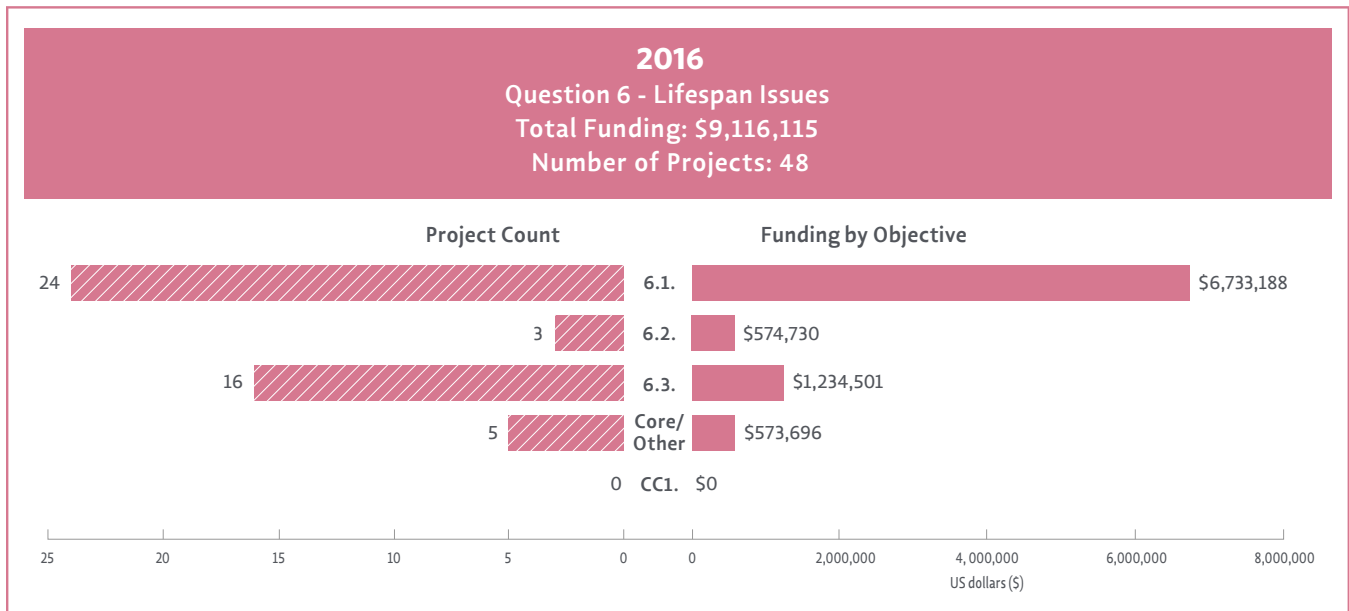


Figure 32. 2016 funding and project count by Question 6 objectives.

QUESTION 6 SUBCATEGORY ANALYSIS

Because Question 6 had so few assigned projects (48 projects) and because many projects encompassed more than one topic, it was difficult to group these research projects into subcategories. However, as the

research field investigating ASD across the lifespan grows and matures, subcategories may be developed for this question area in the future.

PROGRESS MADE ON QUESTION 6 FROM 2008-2016

Research related to Question 6 has received the lowest level of annual funding for every year of the nine-year analysis period (**Figure 33**). Although there was a small increase in funding for this question area from 2009-2010 and 2014-2016, 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 2016. 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 be monitored for progress toward that recommendation in the future.

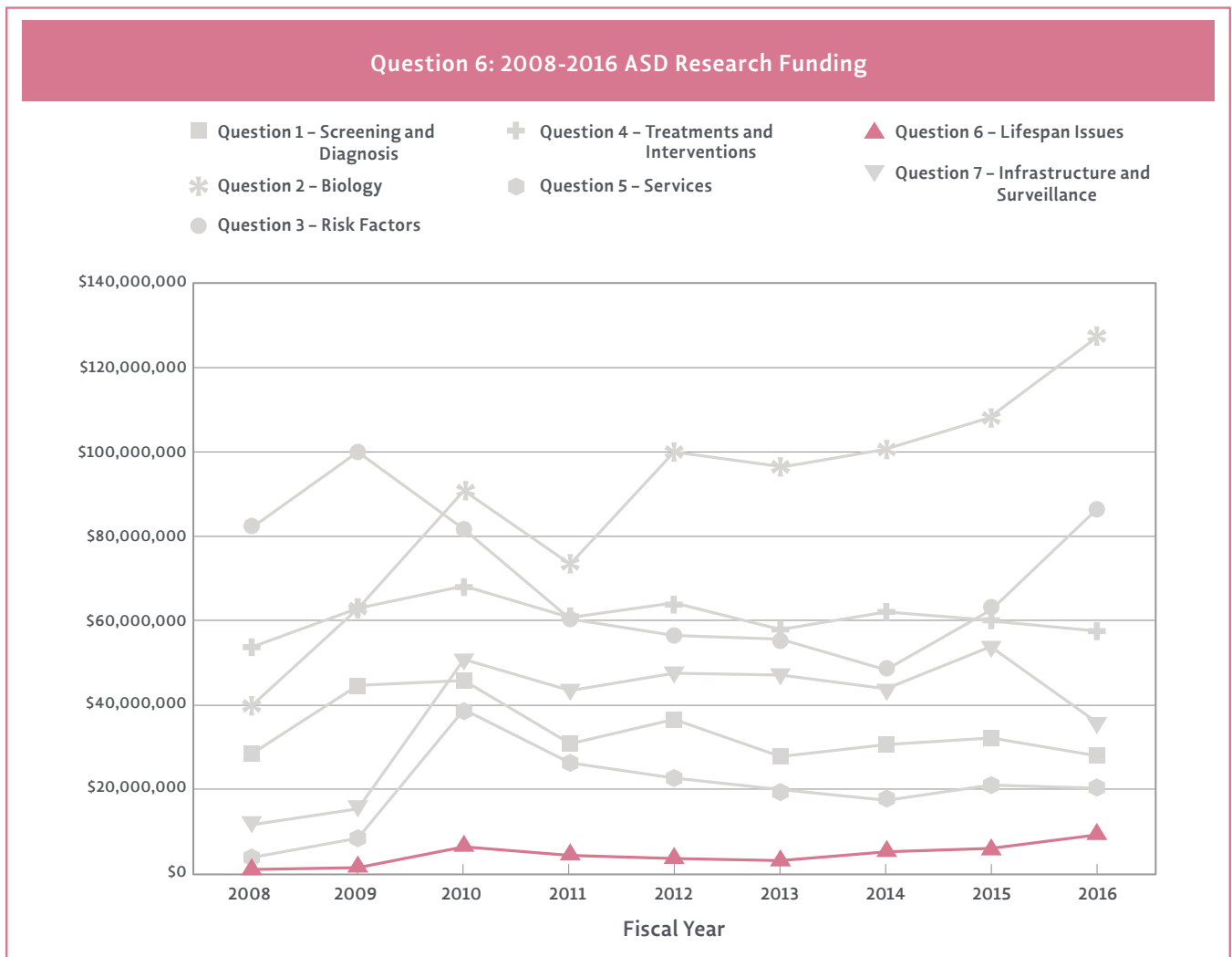


Figure 33. Question 6 ASD research funding from 2008-2016. Funding for Question 6 remained low over the nine-year span but recently experienced a slight increase.



QUESTION 7

INFRASTRUCTURE AND SURVEILLANCE

ASPIRATIONAL GOAL: DEVELOP, ENHANCE, AND SUPPORT INFRASTRUCTURE AND SURVEILLANCE SYSTEMS THAT ADVANCE THE SPEED, EFFICACY, AND DISSEMINATION OF ASD RESEARCH AND SERVICES.

RESEARCH FOCUS OF QUESTION 7

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

A word cloud was made using the project titles listed under this question to describe the research funded in Question 7 in 2016 (depicted above). The size of each word within the word cloud indicates the frequency of its use in project titles. The word cloud visually depicts the main research themes and topics that were associated with projects categorized under Question 7.

ANALYSIS OF 2016 QUESTION 7 PORTFOLIO

Projects assigned to Question 7 comprised 10% (\$36.1 million) of the total ASD research supported in 2016 and consisted of 136 projects, which was 10% of the total number of projects. In 2016, the Simons Foundation, National Institutes of Health 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. **Figure 34** provides 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 2016. The largest portion of funding went towards objective 7.2, which focuses on developing and enhancing data banks and data sharing (\$11.6 million, 32% of funding). Objective 7.2 had 25 projects; this is not the largest share of projects in Question 7, as projects focused on data infrastructure often require more funding per project. Funding towards programs enhancing the research workforce and developing interdisciplinary training (7.3) received the next

largest amount of funding (\$9.9 million, 27%) and greatest portion of projects (58 projects). Objective 7.4 followed with \$7.4 million (21%) in funding and 18 projects; this objective supports the expansion of ASD surveillance systems. Objective 7.1, which supports increasing biospecimen donations and encouraging integration of biorepository banks, was 12% of Question 7 funding (\$4.2 million) and had 17 projects. There were 18 projects, accounting for \$3 million, that did not fit into a specific Question 7 objective and were assigned to Core/Other. 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) focused on understanding girls and women with ASD did not receive any funding under Question 7 in 2016. Research within this 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.

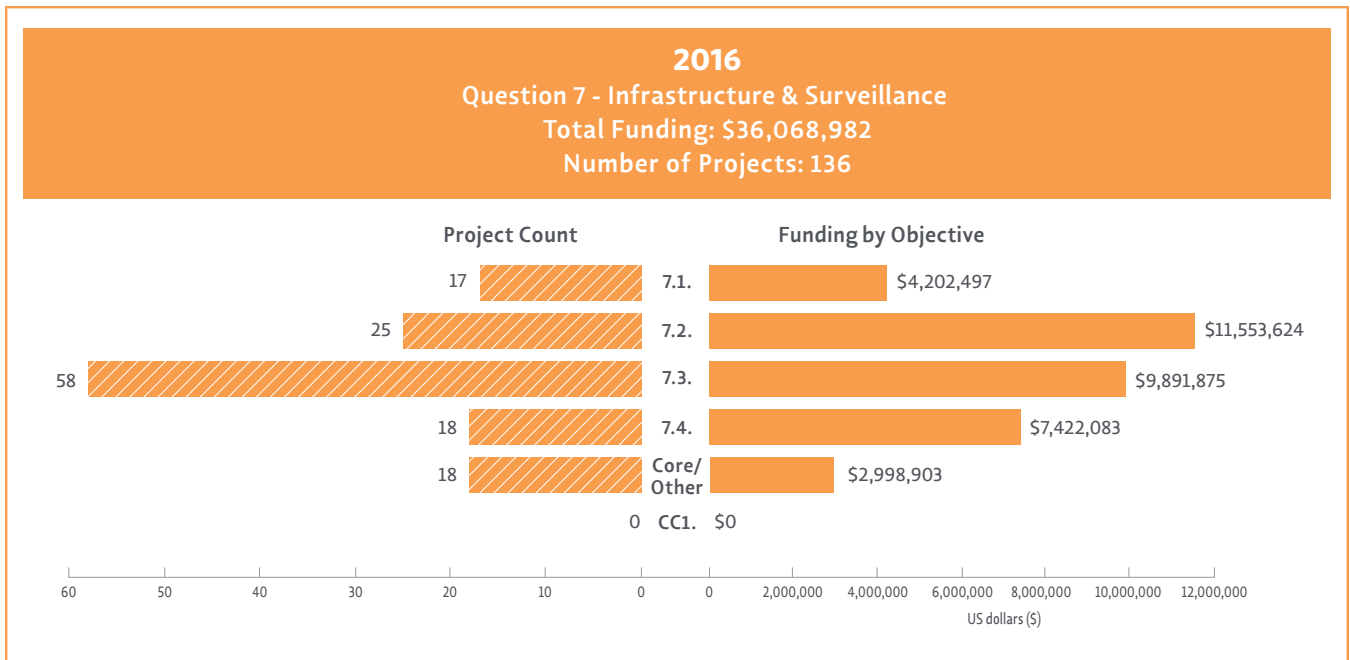


Figure 34. 2016 funding and project count by Question 7 objectives.

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** (Figure 35).

In Question 7, the subcategories encompass a diverse set of project types, with funding distributed relatively evenly across them. In 2016, **Data tools**, such as the National Database for Autism Research (NDAR) and the Autism Genetics Resource Exchange (AGRE), received the largest portion of funding (28%). **Research**

workforce development, which supports conferences and training for autism researchers, accounted for 21% of funding in 2016. **Surveillance and prevalence studies**, such as studies under the ADDM Network, had 18% of Question 7 funding. **Research recruitment and clinical care**, which helps increase participation in research studies and conduct medical evaluations of participants, received 12% of funding. Funding supporting coordinating centers that analyze data and disseminate research to the community are included within **Research infrastructure**, which received 11% of funding. **Biobanks** received 10% of Question 7 funding in 2016.

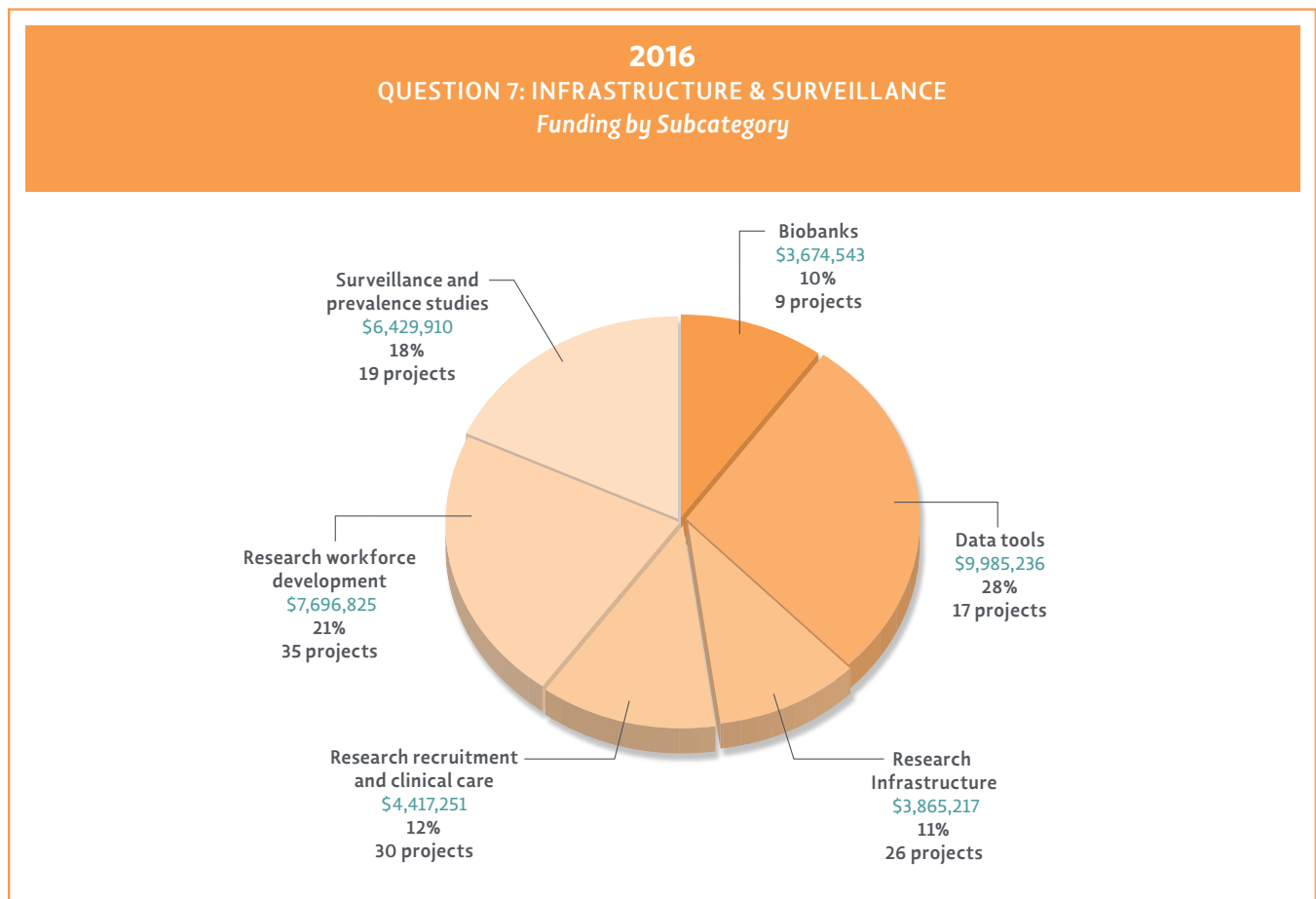


Figure 35. Question 7 funding by subcategory in 2016.

PROGRESS MADE ON QUESTION 7 FROM 2008-2016

Figure 36 shows the trend in Question 7 funding over the nine-year span of 2008-2016. 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 noticed a slight increase in funding for Question 7 research projects, however it was followed by a significant decrease in 2016.

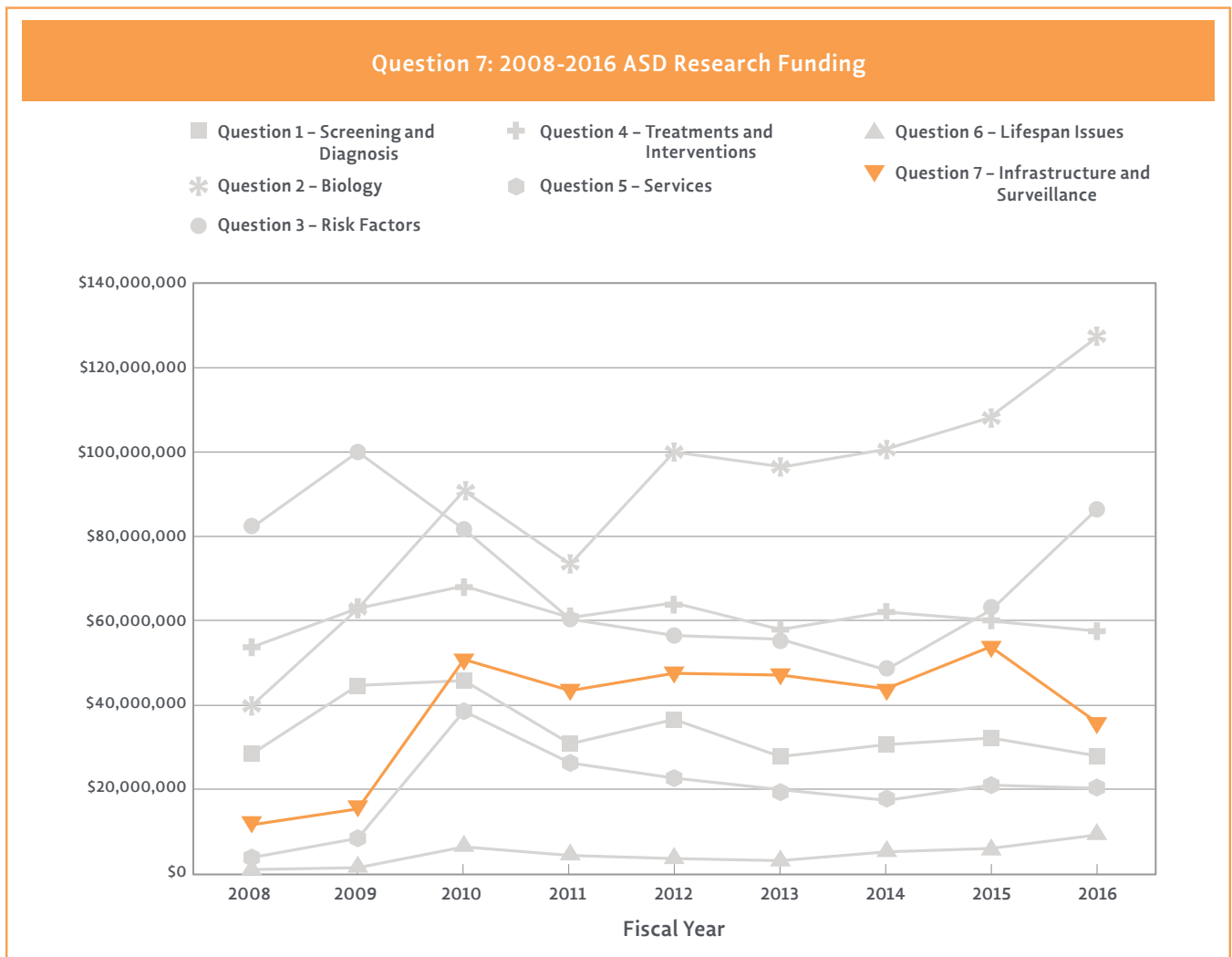


Figure 36. Question 7 ASD research funding from 2008-2016. Following an initial increase from 2008-2010, funding for Question 7 remained relatively flat from 2010-2016.

SUMMARY AND CONCLUSION

The *2016 IACC ASD Research Portfolio Analysis Report* represents the ninth year of data collected and the seventh comprehensive report of U.S. ASD research funding across both the federal and private sectors. It is also the first analysis to measure research progress against the 23 new objectives from the *2016-2017 IACC Strategic Plan*. Project information was collected from 18 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*. In 2016, federal agencies funded 80% of ASD research while private organizations contributed nearly 20% of funding, similar to previous years. Among the participating funders, 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 \$364.4 million and spanned 1,360 projects in 2016. With nine 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 over the period from 2008-2016. Over these nine years, autism research showed an overall upward trend in funding, increasing by 64.3% since 2008.

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. As this was the first year aligning ASD research projects with the new *Strategic Plan* objectives, 2016 will be the starting point to assessing progress on current research priorities within the objectives. However, the *Strategic Plan* question areas have remained unchanged since in their inception in 2008. Therefore, we are able to continue to evaluate the progress in the question research areas from 2008 to 2016. Each *Strategic Plan* question has sustained similar proportions in funding throughout the years. In 2016, funding toward Question 2 (Underlying 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) each comprised nearly one-tenth of the total funding. Lastly, Question 5 (Services) and Question 6 (Lifespan Issues) had the smallest amounts of funding, similar to years prior. It is worth noting that every objective in the *2016-2017 Strategic Plan* had associated projects and funding in 2016, 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, though some areas still have much room for growth.

As in the previous *IACC ASD Portfolio Analysis Reports*, additional analyses on the geographical distribution of autism research funding, investments in long-term (ongoing) research compared to newly funded projects, and the types of research funded by different agencies and organizations were included in the portfolio analysis to provide more detailed information for the Committee and community stakeholders on the autism research landscape. For the first time, the *Portfolio Analysis Report* provided information on international ASD research supported by U.S. funders. In 2016, 1% of total funding went towards research in 19 countries outside the U.S., amounting to \$3.5 million and 49 projects. Also, when examining investments in long-term research compared to newly funded projects among the *Strategic Plan* questions, there was a significant increase in newly funded research on the lifespan (Question 6). Within Question 6, 68% of projects were funded for the first time in 2016, demonstrating growth in investments in this research area.

This annual *IACC ASD Research Portfolio Analysis Report* assists the Committee with carrying out its charge to monitor autism activities and to inform the process of updating the *IACC Strategic Plan* for ASD Research. Future portfolio analyses using the 2016-2017 *IACC Strategic Plan's* set of 23 objectives will continue to serve as a resource for the Committee, funders, and the broader ASD community to monitor progress, identify knowledge gaps, recognize emerging trends and new opportunities, and guide future research investments to better meet the needs of families and individuals affected by ASD.

APPENDICES

APPENDIX A

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.

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 early, evidence-based intervention. Flagship programs include the Autism Intervention Research Networks (**AIR-B and AIR-P**), the Developmental Behavioral Pediatrics Research Network (**DBPNet**), and the Leadership Education in Neurodevelopmental and Related Disabilities (**LEND**) program.

National Institutes of Health (NIH)

The 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 the flagship autism programs funded by NIH, the Autism Centers of Excellence (**ACE**), is 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 United States Armed Forces. Within the DoD's 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.

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. ED also supports funding towards a joint initiative between ED, HHS, Department of Labor, and the Social Security Administration called Promoting Readiness of Minors in Supplemental Security Income (PROMISE), which was created to foster improved health, education, and post-secondary outcomes for children ages 14-16 who receive Supplemental Security Income (SSI), as well as their families.

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 risk 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 work with a particular emphasis on investigation of the biological underpinnings of autism, including immune and metabolic pathways.

Autism Science Foundation (ASF)

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

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.

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.

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 the Simons Foundation Autism Research Initiative (**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. SFARI supports **SPARK**, a large autism research project aimed at collecting medical and genetic information from individuals with autism and their family in an effort to increase the power of autism research for knowledge.

APPENDIX B

ASD-Related Research Projects not included in the *IACC Portfolio Analysis*

This section contains lists of 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.

FUNDER	PRINCIPAL INVESTIGATOR(S)	PROJECT TITLE
PCORI	Forrest, Christopher B.	Development of the PROMIS Pediatric Sleep Health Item Banks
PCORI	dosReis, Susan	Methods for Prioritizing Surrogate Desired Health Outcomes for Patients
PCORI	O'Boyle, Megan	Phelan-McDermid Syndrome Data Network (PMS_DN)
PCORI	Walsh, Kathleen MD	Automating Quality and Safety Benchmarking for Children: Meeting the Needs of Health Systems and Patients
EPA	Alshawabkeh, Akram	Center for Research on Early Childhood Exposure and Development in Puerto Rico
EPA	Bennett, Deborah H.	Tracking Semivolatile Organic Compounds Indoors: Merging Models and Field Sampling to Access Concentrations, Emissions, and Exposures
EPA	McConnell, Rob Scot	Southern California Children's Environmental Health Center
EPA	Kullman, Seth W.; Levin, Edward D.; Slot-kin, Theodore	Establishing an AOP for the Role of the Vitamin D Receptor in Developmental Neurotoxicity
EPA	Karagas, Margaret Rita	Children's Environmental Health & Disease Prevention Research Center at Dartmouth
EPA	Woodruff, Tracey J.	The UCSF Pregnancy Exposures to Environmental Chemicals (PEEC) Children's Center
EPA	Van de Water, Judith	The UC Davis Center for Children's Environmental Health and Disease Prevention
EPA	Murphy, Susan K.	Neurodevelopment and Improving Children's Health following EtS exposure (NICHES)

FUNDER	PRINCIPAL INVESTIGATOR(S)	PROJECT TITLE
EPA	Peterson, Karen E.	Lifecourse Exposures & Diet: Epigenetics, Maturation & Metabolic Syndrome
EPA	Schantz, Susan L.	Novel Methods to Assess the Effects of Chemicals on Child Development
SAMHSA	Oppenheim, Jennifer	Project LAUNCH Grant Program
SAMHSA	Donato, Ingrid	Project Advancing Wellness and Resilience Education (AWARE)
SAMHSA	Donato, Ingrid	KnowBullying App
SAMHSA	Robinson, Captain Maryann	National Child Traumatic Stress Initiative (NCTSI) - LIJ Medical Center of Northwell Health
SAMHSA	Blau, Gary	Comprehensive Community Mental Health Services for Children and Their Families (CMHI)
SAMHSA	Johnson, Kimberly	Behavioral Health Treatment Locator
NIH	Thompson, Paul	Enigma Center for Worldwide Medicine, Imaging & Genomics
NIH	Brueckner, Martina	Genetics and Genomics of Congenital Heart Disease and Associated Neurodevelopmental Abnormalities
NIH	Newburger, Jane W.	The Genomic Basis of Congenital Heart Disease and Neurodevelopmental Outcomes
NIH	Srivastava, Deepak	Genetics of Hypoplastic Left Heart Syndrome
NIH	Tristani-Firouzi, Martin	Bridging the Gap Between Genomics and Clinical Outcomes in CHD
NIH	Lander, Eric S	Center for Common Disease Genetics
NIH	Darnell, Robert B.	New York Center for Collaborative Research in Common Disease Genomics
NIH	Cobrinik, David	Modeling Optic Nerve Hypoplasia with Patient iPSC-Derived Retinal Ganglion Cells

FUNDER	PRINCIPAL INVESTIGATOR(S)	PROJECT TITLE
NIH	Hodzic, Didier	Nuclear Dynamics in Retinal Development and Homeostasis
NIH	Brown, Nadean L.	Investigation of Mammalian Retinal Neuron Development
NIH	Feldheim, David A.	Development of retinal ganglion cell types
NIH	Binkley, Catherine J.	Oral Health Promotion (OHPROM) Strategy for Persons with Intellectual & Developmental Disabilities
NIH	Usdin, Karen P.	The Consequences of Repeat Expansion in the Fragile X-Related Disorders
NIH	Usdin, Karen P.	Mechanism of Repeat Expansion and Chromosome Fragility in Fragile X Syndrome
NIH	Yang, Wei	Brain-Lesioned Patient Database Core
NIH	Gusella, James F.	Neurodevelopmental Loci
NIH	Troyanskaya, Olga	Integration and Visualization of Diverse Biological Data
NIH	Hagerman, Paul J.	Epigenetic Regulation of the FMR1 Gene
NIH	Wilcox, Allen J.	Epidemiologic Study Of Reproductive Outcomes And Environmental Exposures
NIH	Lein, Pamela J.	Molecular and Cellular Basis of PCB Developmental Neurotoxicity
NIH	Alshwabkeh, Akram N.	Environmental Influences on Child Health Outcomes in Puerto Rico (ECHO-PRO)
NIH	Vena, John Edward	Exposome Contributors to Child Health Originating from National Fetal Growth Study (ECCHO-NFGS)
NIH	Dennerly, Phyllis A.	Rhode Island Child Clinical Trials Collaborative
NIH	Sullivan, Janice E.	The Kentucky Pediatric Clinical Trials Rural/Urban Partnership
NIH	O'Shea, Michael	Environment, Epigenetics, Neurodevelopment & Health of Extremely Preterm Children
NIH	Dunlop, Anne Lang	The Impact of the Intrauterine and Early Child-hood Environments on Neurocognitive and Met-abolic Development in African American Youth: Focus on the Gut-Brain Axis

FUNDER	PRINCIPAL INVESTIGATOR(S)	PROJECT TITLE
NIH	Zhu, Lin L.	Using fMRI to Understand Verbal and Nonverbal Human Communication
NIH	Alberts, Jeffrey R.	Mother-Offspring Microbiome as Perinatal Substrate for Neurobehavioral Development
NIH	Gros-Louis, Julie J.	Caregiver Response Styles and Infant Attention: Relations to Language Development
NIH	Porter, Forbes	Inborn Errors of Cholesterol Synthesis
NIH	Guralnick, Michael J.	Intellectual and Developmental Disabilities Research Center
NIH	Gilmore, John H.	Early Brain Development in One and Two Year Olds
NIH	Portera-Cailliau, Carlos	Imaging dendritic spine abnormalities and circuit defects in fragile X mice
NIH	Lester, Barry M.	Neonatal Neurobehavior and Outcomes in Very Preterm Infants
NIH	Yuan, Hongjie	NMDAR Mutations & Neurodevelopmental Disorder: from Mechanism to Targeted Therapy
NIH	Johnson, Scott P.	Social Attention in Infancy
NIH	Chen, Lu	Developmental Pathophysiology of Synapses in a Mouse Model of Fragile X Syndrome
NIH	Chin, Frederick T.	Cross-Species Multi-Modal Neuroimaging to Investigate GABA Physiology in Fragile X Syndrome
NIH	Darnell, Jennifer C.	Cell-Specific RNA Targets of the Fragile X Mental Retardation Protein Family
NIH	Donnelly, Joseph E.	Weight Management for Adolescents With IDD
NIH	Hagerman, Paul J.	Expression of the Fragile X Gene
NIH	Houser, Carolyn R.	GABA System Alterations and Fragile X Syndrome
NIH	Huber, Kimberly	Mechanisms of Neocortical and Sensory Hyperexcitability in Fragile X Syndrome
NIH	Huber, Kimberly	Molecular and Synaptic Mechanisms of Auditory Circuit Dysfunction in FXS Mice

FUNDER	PRINCIPAL INVESTIGATOR(S)	PROJECT TITLE
NIH	Huber, Kimberly	Auditory Processing Deficits in Fmr1 KO Mice
NIH	Huber, Kimberly	Neurophysiological and Acute Pharmacological Studies in FXS Patients
NIH	Lipton, Jonathan Oren	Sleep and Circadian Rhythms in Tuberous Sclerosis Complex
NIH	Mailick, Marsha Ruth	Fmr1 Premutation Phenotypes in Population-Based & Clinically-Ascertained Samples
NIH	Mandel, Gail	The Mechanism of Rett Syndrome Rescue by Astrocytes
NIH	Percy, Alan Kenneth	Rett Syndrome; MECP2 Duplications; and Rett-Related Disorders Natural History
NIH	Percy, Alan Kenneth	MECP2 Duplication Syndrome: Longitudinal Studies; Biomarker and Clinical Outcome Development
NIH	Percy, Alan Kenneth	Rett-Related Disorders: Longitudinal Studies; Biomarker and Clinical Outcome Development
NIH	Percy, Alan Kenneth	Development of a Behavioral Outcome Measure for Rett Syndrome (RettBe) and Metabolic Profiling of Rett Syndrome; Mecp2 Duplication Syndrome; and Rett-Related Disorders
NIH	Richter, Joel D.	Rescuing the Fragile X Syndrome by CPEB Depletion
NIH	Richter, Joel D.	Strategies to Rescue PI3K Dysregulation in Fragile X Syndrome
NIH	Richter, Joel D.	Rescuing Fragile X Syndrome by Targeting P70 S6 Kinase 1
NIH	Abbeduto, Leonard	Expressive Language Sampling as an Outcome Measure
NIH	Johnson, Scott	Constraints on Visual Statistical Learning in Infancy
NIH	Snider, William D.	Imaging Core NINDS Institutional Center Core Grants to Support Neuroscience Res
NIH	Boyden, Edward S.	Millisecond-Timescale Whole-Brain Neural Activity Mapping in Health and Disease

FUNDER	PRINCIPAL INVESTIGATOR(S)	PROJECT TITLE
NIH	Ladt, Kelsey Curd	Dissecting the Microarchitecture and Dynamics of Axonal Actin
NIH	Dobyns, William	The genetic basis of Dandy-Walker and other mid-hindbrain malformations
NIH	Iwase, Shigeki	Neutralizing epigenomes in neurodevelopment disorders
NIH	Macdonald, Robert	GABA(A) Receptor Assembly/Trafficking/Function and Epilepsy Missense Mutations
NIH	Sherr, Elliott	ACC: Callosal Agenesis as a Window into Common Neurodevelopmental Disorders
NIH	Hauswirth, Anna	Characterization of Class II PI3-kinase as a homeostatic synaptic plasticity gene
NIH	Cherra, Salvatore	Understanding the molecular mechanisms that maintain excitation-inhibition balance in neural circuits
NIH	Saldate, Johnny	Post-translational modifications of tomosyn and synaptic plasticity
NIH	Tolias, Kimberly	Signaling Mechanisms Regulating Rac-dependent Synaptic and Dendritic Development
NIH	Sagerstrom, Charles	Molecular Analysis of Hindbrain Development
NIH	Masino, Susan	Fifth Global Symposium on Ketogenic Therapies
NIH	Nelson, Sacha	Homeostatic Regulation of Neocortical Inhibition

APPENDIX C

Subcategory Definitions



QUESTION 1: SCREENING AND DIAGNOSIS

Diagnostic and screening tools

This subcategory includes projects that are developing new autism diagnostic and screening tests, as well as those establishing the usefulness of new or revised assessments for autism symptoms. It also encompasses projects aimed at adapting clinical assessments into other languages for use in multi-lingual community settings and non-U.S. countries.

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 symptoms, including both biological and behavioral characteristics. 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 impairments can contribute to symptom development 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 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 risk factors for 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 risk for 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 increased risk for ASD or to better understand genetic risk 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.

Complementary, dietary, and alternative

This subcategory includes research on acupressure; acupuncture; 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.

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

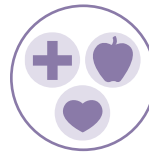
Animal models mimicking behaviors of ASD and those that are being used to develop or test new drug treatments, as well as cell lines used to discover new drug targets or to screen potential drug candidates, are included in this subcategory.

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.

**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

Due to the small number of projects (48) and the significant overlap between topics covered in these projects, no subcategories were created for this question in the *2016 Portfolio Analysis Report*. As the research field grows, subcategories that encapsulate the scope of projects in this question may be defined in the future.



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 and 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 the dissemination of 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).

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