INTERAGENCY AUTISM COORDINATING COMMITTEE

2013 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)

IACC INTERAGENCY AUTISM COORDINATING COMMITTEE

OFFICE OF AUTISM RESEARCH COORDINATION
NATIONAL INSTITUTES OF HEALTH

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ABOUT THE IACC

The Interagency Autism Coordinating Committee (IACC) is a Federal advisory committee charged with coordinating all activities concerning autism spectrum disorder (ASD) within the U.S. Department of Health and Human Services (HHS) and providing advice to the Secretary of HHS on issues related to autism. It 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 families and individuals 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 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**.

2013 IACC AUTISM SPECTRUM DISORDER RESEARCH PORTFOLIO ANALYSIS REPORT

INTRODUCTION & ANALYSIS FRAMEWORK

In 2009, the Interagency Autism Coordinating Committee (IACC) launched its *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 consumer-focused "questions." The questions are divided further into research objectives that address key research needs, gaps, and opportunities identified by the Committee. Each objective includes a recommended budget that serves as an estimate of how much the Committee projects it might cost to conduct the research-related activities described. The *IACC Strategic Plan* was updated in 2010 and 2011, leading to a total of 78 objectives on autism research.

Following the development of the *IACC Strategic Plan*, the Office of Autism Research Coordination—the office within the National Institutes of Health (NIH) that manages the activities of the IACC—began issuing a series of *IACC Autism Spectrum Disorder (ASD) Research Portfolio Analysis Reports* to provide the IACC with comprehensive information about the status of autism research funding among Federal agencies and private research organizations in the 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 gone toward support of 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 toward achievement of objectives in the *IACC Strategic Plan for ASD Research*. The *2013 IACC ASD Research Portfolio Analysis Report*, in addition to information on progress made toward each of the 78 objectives in the *IACC Strategic Plan* in 2013, also provides an analysis of progress that was made over the six-year period from 2008-2013.

To accompany the *IACC 2013 ASD Research Portfolio Analysis Report*, detailed 2013 Federal and private organization project data are available in the *Autism Research Database*, a database accessible via the IACC website (**https://iacc.hhs.gov/funding/data/**). Launched in 2012, 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.

IACC Strategic Plan Questions and Corresponding Research Areas

The Office of Autism Research Coordination (OARC) requested 2013 autism-related research project and funding information from several Federal agencies and private organizations, including the annual budget for each project and its relevance to the seven critical questions/chapters of the *2011 IACC Strategic Plan for ASD Research*, illustrated below (**Figure 1**).

Figure 1. The research areas corresponding to the seven questions of the *2011 IACC Strategic Plan for ASD Research* are represented by the icons to the left of each question.

Subcategory Classification

In 2010, OARC introduced the subcategory classification system (**Figure 2**) to the *IACC Portfolio Analysis Report* to help the Committee and other readers of this report better understand the types of research encompassed by the projects in the research portfolio —especially those projects that are categorized as outside the objectives of the *Strategic Plan* but within a question's research area. For the subcategory analysis, each project in the *2013 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: Diagnostic and screening tools, Early signs and biomarkers, Intermediate phenotypes/Subgroups, and Symptomology.

IACC STRATEGIC PLAN QUESTIONS AND CORRESPONDING RESEARCH AREAS BY SUBCATEGORY

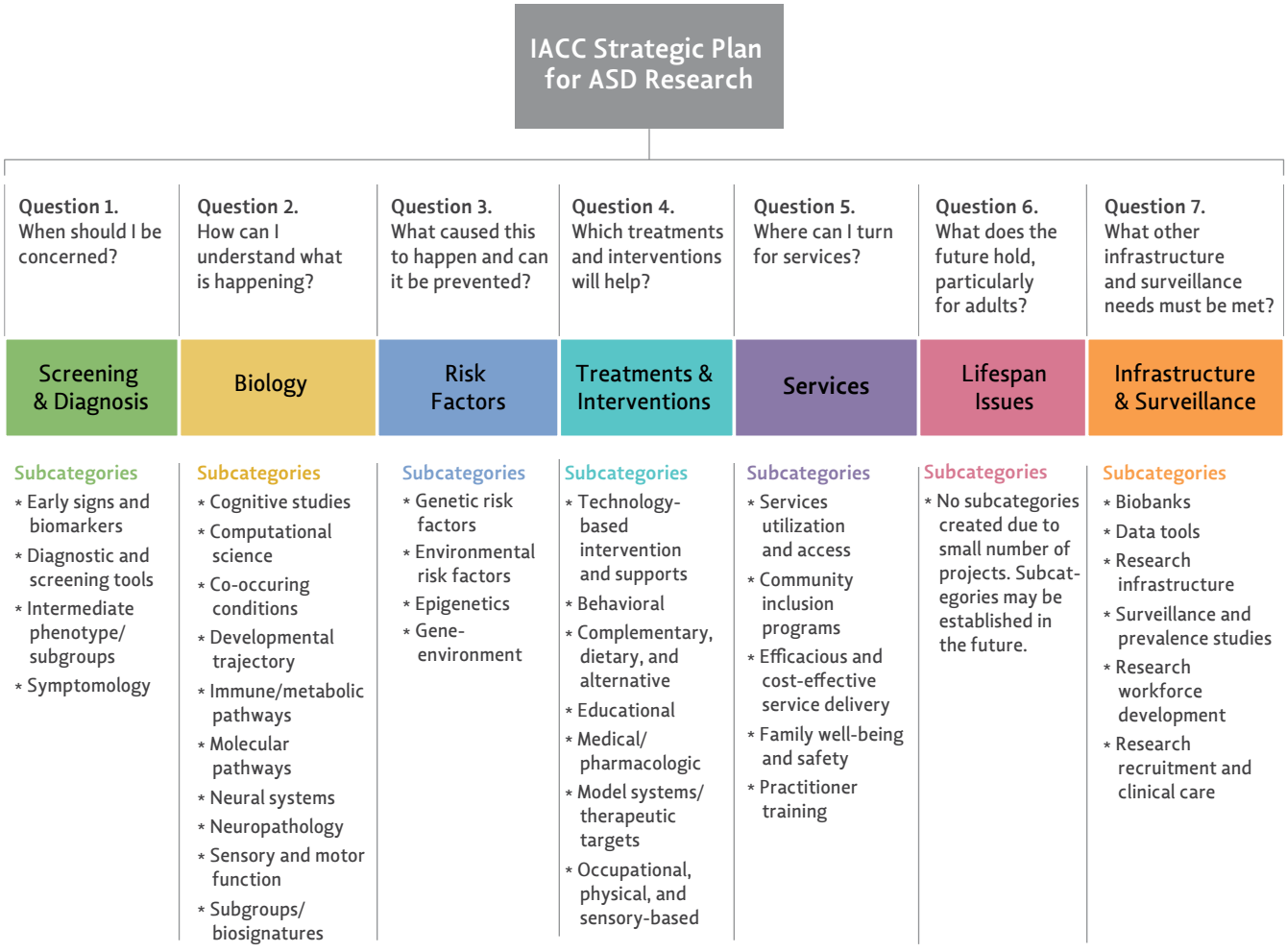


Figure 2. A subcategory classification system was created to allow an understanding of the autism research portfolio based on simple research topics that are relevant to each of the *IACC Strategic Plan* questions. Appendix D provides detailed definitions of the subcategory research areas.

ASD RESEARCH FUNDERS AND FUNDING IN 2013

Who funded ASD research in 2013?

Ten Federal agencies and eight private funders provided their autism funding data for this analysis. These 18 agencies and organizations are listed in **Table 1**. The Patient-Centered Outcomes Research Institute (PCORI) is a new private funder submitting ASD research to the *IACC Portfolio Analysis*. PCORI was authorized by the *Patient Protection and Affordable Care Act of 2010* to fund comparative clinical effectiveness research to help inform healthcare decision-making. Some funders included in previous years' *Portfolio Analysis Reports* either did not have projects to report in 2013 or did not choose to participate in this year's analysis. Brief summaries of the mission areas and portfolios of the different Federal agencies and private organizations included in this analysis appear in **Appendix A**.

AGENCIES AND ORGANIZATIONS INCLUDED IN THE *2013 IACC PORTFOLIO ANALYSIS*

FEDERAL AGENCIES	PRIVATE ORGANIZATIONS
• Administration for Children and Families (ACF) • Agency for Healthcare Research and Quality (AHRQ) • Centers for Disease Control and Prevention (CDC) • Centers for Medicare & Medicaid Services (CMS) • Department of Defense (DoD)* – Air Force (AF) – Autism Research Program (ARP) • Department of Education (ED) • Environmental Protection Agency (EPA) • Health Resources and Services Administration (HRSA) • National Institutes of Health (NIH) • National Science Foundation (NSF)	• Autism Research Institute (ARI) • Autism Science Foundation (ASF) • Autism Speaks (AS) • Brain & Behavior Research Foundation (BBRF) • Center for Autism and Related Disorders (CARD) • Organization for Autism Research (OAR) • Patient-Centered Outcomes Research Institute (PCORI) • Simons Foundation (SF)

** The DoD Autism Research Program and Air Force reported as two separate entities for the purpose of this Portfolio Analysis.*

Table 1. Projects from ten Federal agencies and eight private organizations were included in the *2013 IACC Autism Spectrum Disorder Research Portfolio Analysis Report*.

How much ASD research was funded in 2013?

Combined, the estimated Federal and private investment in ASD research in 2013 was $305,580,132. While overall funding for autism research decreased by $26 million from 2012 to 2013, the proportion of Federal and private funding remained relatively constant over this period, with the proportion only shifting by roughly 2% from Federal to private since 2012. In 2013, the Federal government provided 76% ($232.6 million) and private organizations provided 24% ($72.9 million) of the total funding for ASD research (**Figure 3**).

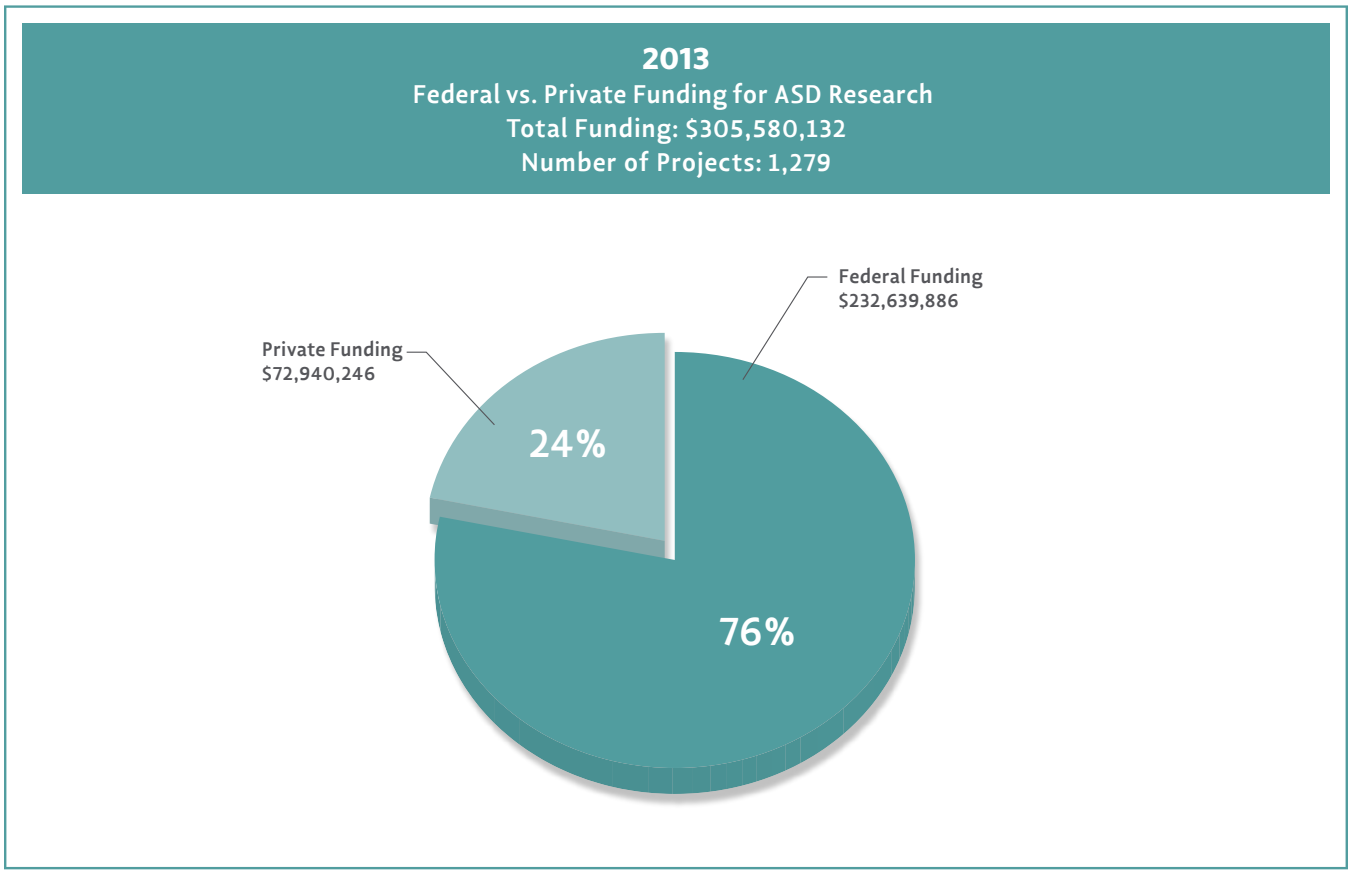


Figure 3. In 2013, 76% of ASD research was provided by Federal sources, while 24% of funding was provided by private organizations.

What funding trends were observed?

- Combined Federal and private investment in ASD research decreased from 2012 ($331.9 million) to 2013 ($305.6 million) (**Figure 4**).
- Private investment in ASD research was higher in 2013 ($72.9 million) than in previous years ($66.8 million in 2011 and $71.8 million in 2012).
- The amount of Federal investment in autism research reported in 2013 ($232.6 million) was lower than the amount reported in 2012 ($260.1 million), and slightly lower than the 2011 level ($233.1 million).
- As stated in previous *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 those years.
- One factor that may have contributed to the decrease in Federal funding for ASD research from 2012 to 2013 is that the overall budget of the National Institutes of Health (NIH), the largest Federal funder of ASD research, was reduced from $30.8 billion in 2012 to $29.1 billion in 2013.
- While one new private funder (the Patient-Centered Outcomes Research Institute) was added to the *2013 Portfolio Analysis*, the new funder contributed only one project in 2013, so the impact on the total funding was relatively small.

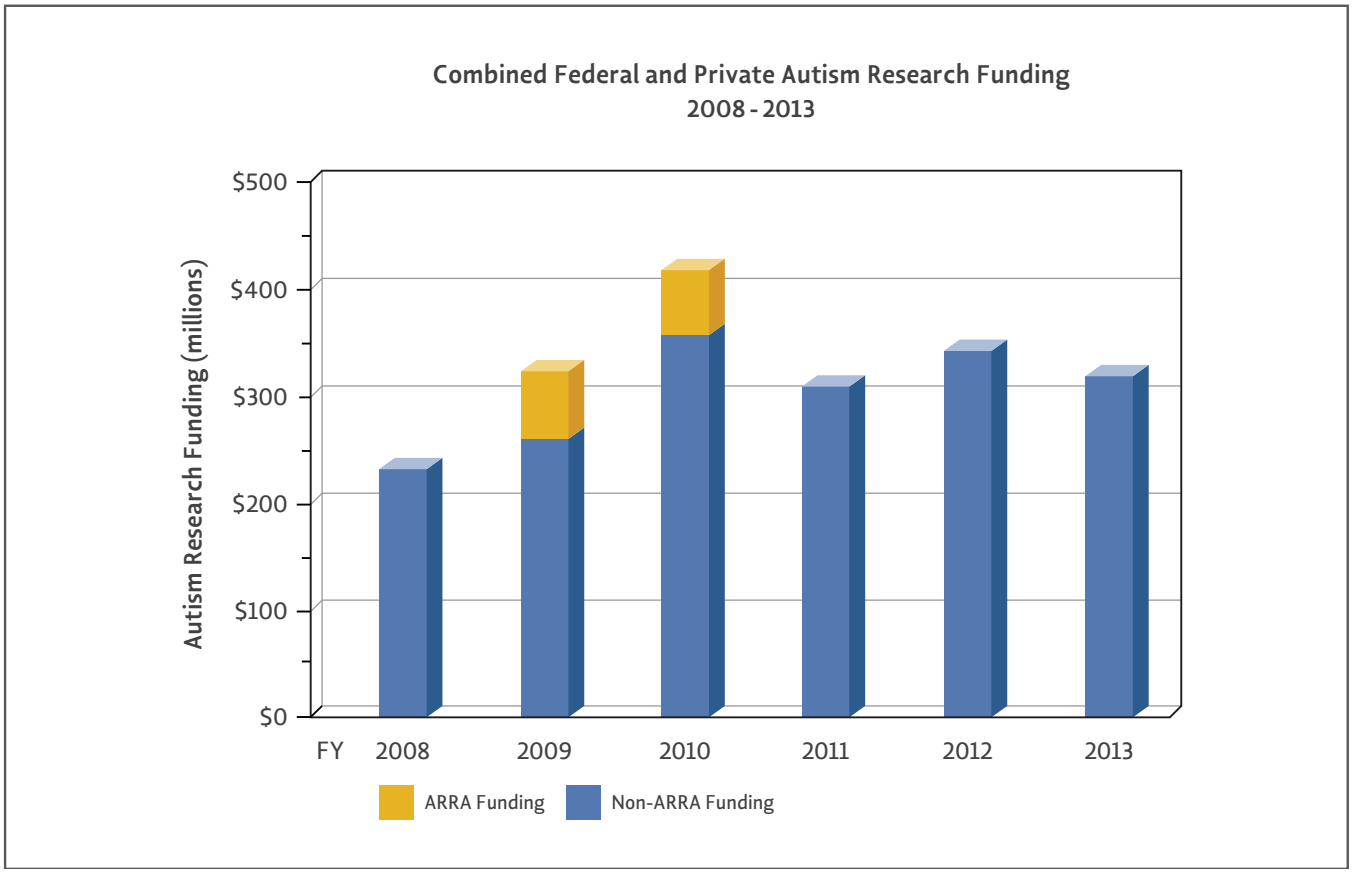


Figure 4. This figure illustrates levels of autism research funding from combined Federal and private sources during 2008-2013 based on data collected for the *IACC Portfolio Analysis* of those years.

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

Figure 5 shows the distribution of autism research projects across the U.S. funded by both Federal agencies and private organizations in 2013. 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. **Table 2** also provides some additional information about the institutions and states that had a large number of projects in 2013.

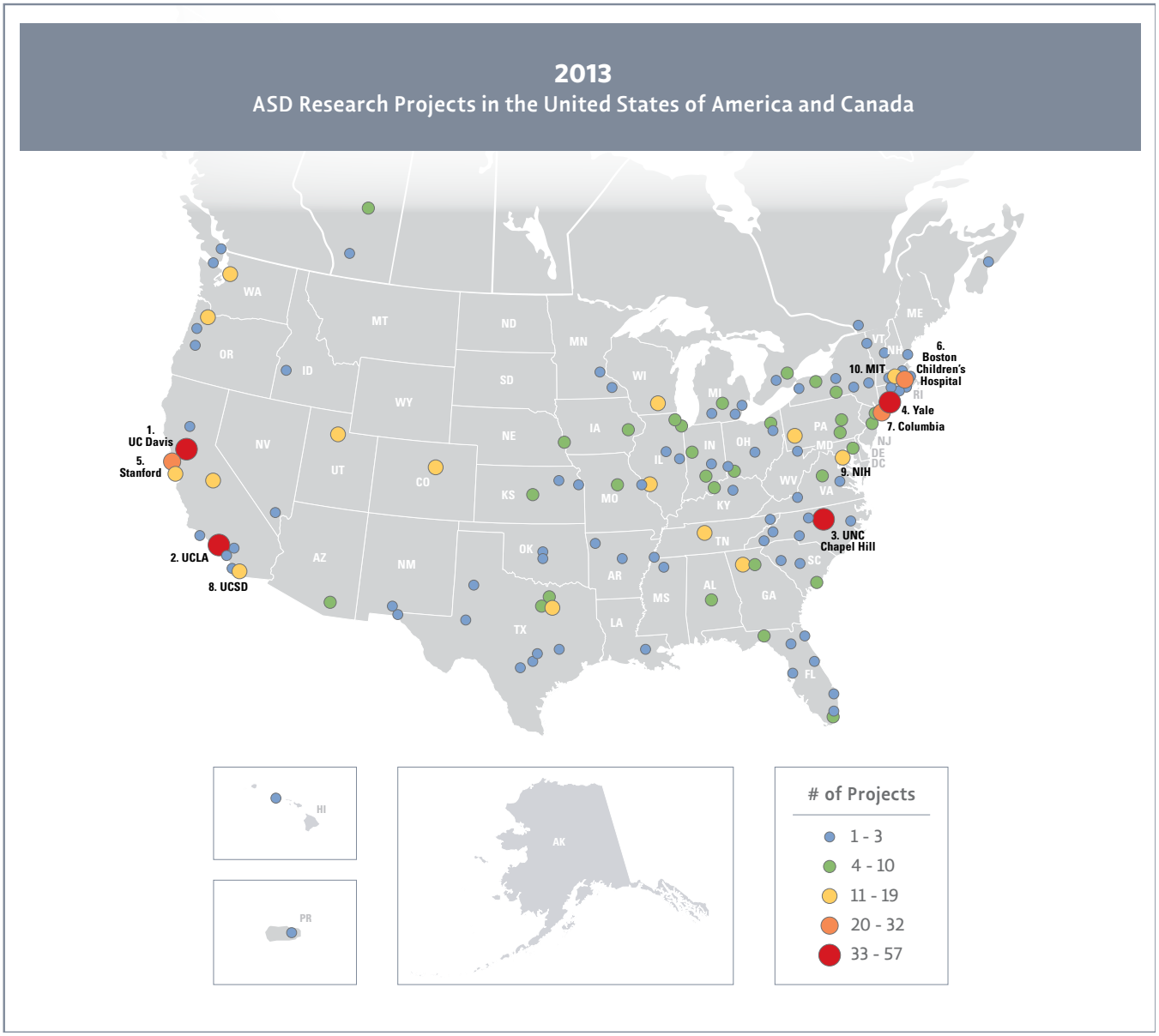


Figure 5. A map of the U.S. and Canada displaying the distribution of autism-related research projects funded by Federal agencies and private organizations.

Which U.S. institutions received the most autism research funding in 2013?		
Institution	**2013 Funding**	**2013 Project Count**
National Institutes of Health – Intramural Research Program	$ 21,775,796	17
University of California, Los Angeles	$ 17,361,222	45
University of California, Davis	$ 16,603,446	54
University of North Carolina, Chapel Hill	$ 13,905,807	38
Yale University	$ 9,141,660	36
Columbia University	$ 8,566,328	22
Massachusetts Institute of Technology	$ 7,758,566	14
Boston Children's Hospital	$ 6,969,353	23
Stanford University	$ 6,483,950	31
University of California, San Diego	$ 5,697,893	18

Which states received the most autism research funding in 2013?		
State	**2013 Funding**	**2013 Project Count**
California	$ 64,365,170	261
Massachusetts	$ 36,163,166	127
New York	$ 31,419,366	132
North Carolina	$ 17,636,048	63
Connecticut	$ 15,289,885	51

Table 2. Institutions and states with the most ASD-related research funding from Federal and private sources in 2013.

How much ASD research funding did each funder provide in 2013?

Each of the 18 stakeholders, agencies, and organizations that participated in the *2013 Portfolio Analysis* had ASD research projects that were active in 2013. In all, 1,279 projects were funded in 2013, totaling $305,580,132 (**Table 3**).

The National Institutes of Health (NIH) was the leading Federal (and overall) contributor of funding for ASD research in 2013 with a total of $175.9 million, funding 410 projects. NIH funding for autism research decreased by $14.7 million from 2012 to 2013; the agency experienced a $1.7 billion reduction in overall budget during the same period. The next largest Federal funder in autism research was the Department of Education, with $22.7 million, followed by the Centers for Disease Control and Prevention (CDC), with $16.1 million. The Department of Education experienced a $6.8 million decrease in funding from 2012 to 2013, while CDC funding in autism research stayed the same. As in previous years, the Simons Foundation and Autism Speaks were the largest private funders of ASD research in 2013, with investments of $50.4 million and $18.6 million, respectively. The percentage of overall ASD research funding provided by each agency is depicted in **Figure 6**.

2013 ASD RESEARCH FUNDING BY AGENCY/ORGANIZATION

Funding Agency/Organization	Project Count	2013 Funding
National Institutes of Health (NIH)	410*	$175,908,374
Simons Foundation (SF)	267	$50,445,045
Department of Education (ED)	130	$22,716,258
Centers for Disease Control & Prevention (CDC)	26	$16,077,048
Autism Speaks (AS)	183	$18,632,127
Health Resources and Services Administration (HRSA)	25	$7,201,186**
Department of Defense – Army (DoD-Army)	49	$4,514,151
National Science Foundation (NSF)	38	$2,349,449
Patient-Centered Outcomes Research Institute (PCORI)	1	$1,757,884
Environmental Protection Agency (EPA)	1	$1,660,178
Agency for Healthcare Research and Quality (AHRQ)	6	$1,233,747**
Department of Defense – Air Force (DoD-AF)	1	$966,000
Centers for Autism and Related Disorders (CARD)	19	$602,300
Brain & Behavior Research Foundation (BBRF)	49	$562,986
Autism Science Foundation (ASF)	28	$389,000
Organization for Autism Research (OAR)	20	$340,235
Autism Research Institute (ARI)	24	$210,669
Centers for Medicare & Medicaid Services (CMS)	1	$13,495
Administration for Children & Families (ACF)	1	$0
Total	**1,279**	**$305,580,132**

**The NIH project number shown reflects unique NIH projects. Projects 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 is counted as a separate project.*

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

Table 3. The table lists the total funding and number of projects provided by the 18 Federal agencies and private organizations included in the *2013 Portfolio Analysis*. Together, the agencies and organizations funded 1,279 projects in 2013, representing an overall investment of $305,580,132.

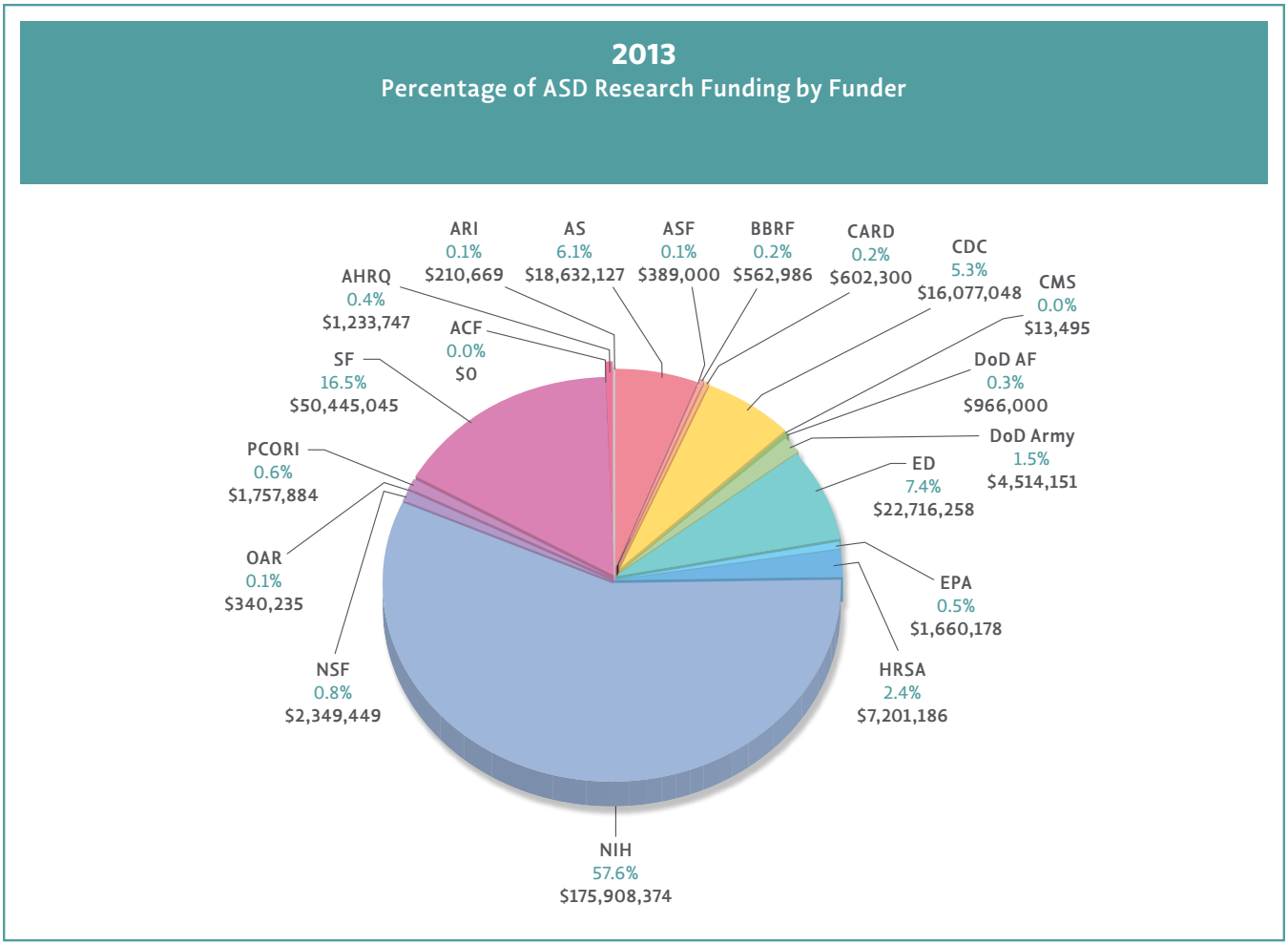


Figure 6. The figure illustrates the percentage of total ASD research funding contributed by the 18 Federal agencies and private organizations included in the *2013 Portfolio Analysis*. NIH provided the largest proportion of funding (57.6%), while Simons Foundation made the largest contribution of the private organizations (16.5%).

Summary of ASD Research Funding in 2013

As outlined in this section, numerous Federal and private funders invested in ASD research conducted across the country in 2013. Funding for the overall autism research portfolio decreased 8.0% from 2012 to 2013, with Federal funding falling 10.6% and private funding growing 1.6%. Over the six-year span from 2008-2013, funding increased by 38%, suggesting continued overall growth in support of ASD research.

ASD RESEARCH AREAS AND PROGRESS IN 2013

What areas of ASD research were funded in 2013?

To better understand what areas of research were funded in 2013, projects were aligned with the corresponding questions in the *2011 IACC Strategic Plan*. **Figure 7** illustrates the breakdown of the research funding according to the *Strategic Plan's* seven questions 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 be in need of additional attention or development.

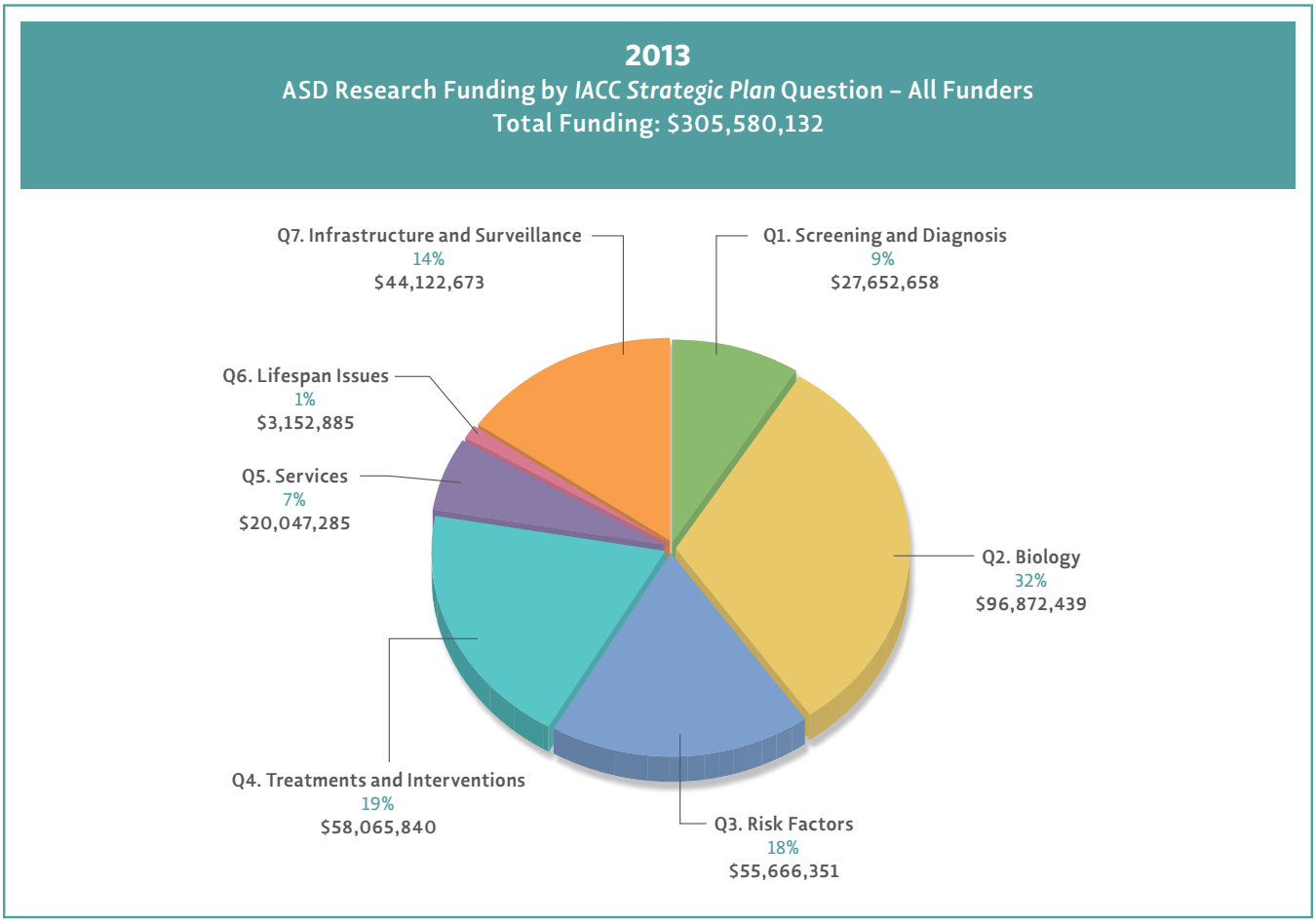


Figure 7. Topic areas are defined by each question in the *IACC Strategic Plan*. The seven questions of the *Strategic Plan* are represented in the clockwise direction, beginning with Screening and Diagnosis (**Question 1**) and ending with Infrastructure and Surveillance (**Question 7**).

ASD research funding in 2013 supported projects relevant to all seven of the critical 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 (32%). This was followed by research into treatments and interventions (Question 4) for ASD (19%), including behavioral therapies, pharmacological treatments, and technology-based interventions. Question 3, research aimed at identifying potential causes and risk factors for the disorder, followed closely with 18% of total funding. Investment in research infrastructure and surveillance (Question 7) stayed the same as 2012 at 14%. Research to improve screening and diagnosis (Question 1) of ASD showed the largest change —a 2% decrease—from 11% in 2012 to 9% in 2013. Research focused on services (Question 5) and lifespan issues (Question 6) remained the smallest areas of funding (7% and 1%, respectively). The percentages of funding for each question were similar to those seen in 2012.

When the number of active projects that align with each question, as opposed to the total funding for these projects is considered, the distribution is subtly different due to differences in the relative sizes of projects falling under each of the seven question categories. In 2013, the percentage of total projects aligned with each question were as follows: Question 1, 10%; Question 2, 37%; Question 3, 11%; Question 4, 20%; Question 5, 10%; Question 6, 2%; Question 7, 9% (**Figure 8**). For example, the number of projects aligning with Question 5 is considerably greater than might be expected based on the proportion of overall funding aligning with this question, demonstrating that individual projects in this area tend to be smaller in size. In contrast, there are fewer projects aligning with Question 3 and Question 7 than might be expected based on the percentages of funding. This indicates that the size of the awards for infrastructure and surveillance projects (Question 7) and projects related to investigation of risk factors (Question 3) tend to be larger, reflecting the greater cost that would be expected for carrying out research in these areas, which often require large-scale studies (Question 3) and database/biobank development and maintenance (Question 7). **Figure 8** shows the distribution of active projects among the *Strategic Plan* questions.

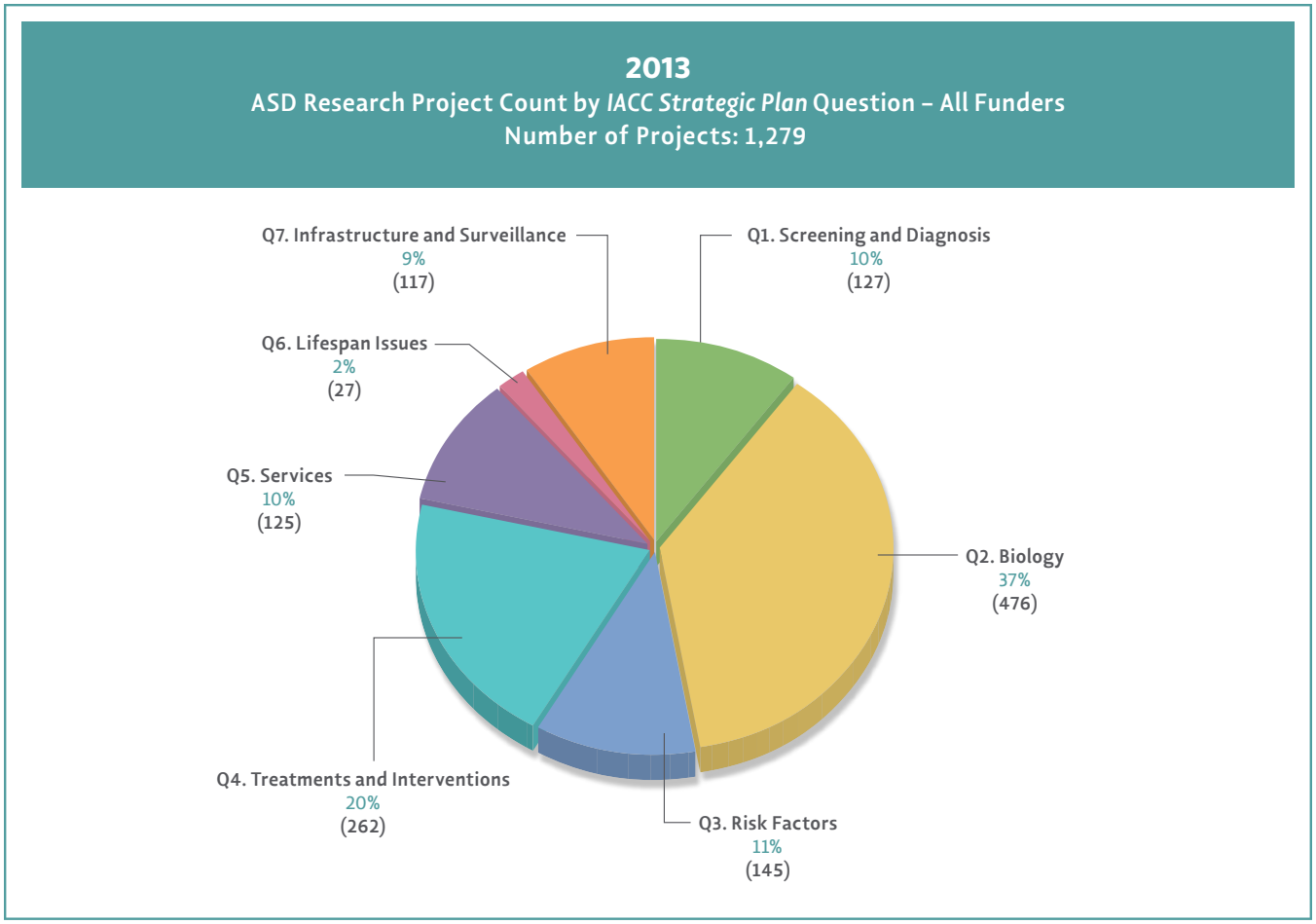


Figure 8. 2013 projects aligned to *Strategic Plan* questions.

How many new research projects were added in 2013 compared to ongoing research?

Each project included in the *Portfolio Analysis* is classified as either "Ongoing" or "New." Ongoing projects were active in the previous year (2012), and new projects became active and received funding for the first time in the current year of the analysis (2013). In 2013, approximately 77% of overall ASD research funding went to ongoing projects while 23% went to new projects. Since most research projects are funded for a duration of multiple years of work, a larger number of ongoing projects compared with new projects would be expected.

However, it is interesting to note that research related to screening and diagnosis (Question 1) and research related to lifespan issues (Question 6) had higher proportions of funding devoted to new projects compared with the overall average. In contrast, funding for infrastructure and surveillance (Question 7) had a higher portion of funding going to ongoing projects, which would be expected due to the long-term infrastructure and data resources these projects provide to the autism research community (**Figure 9**).

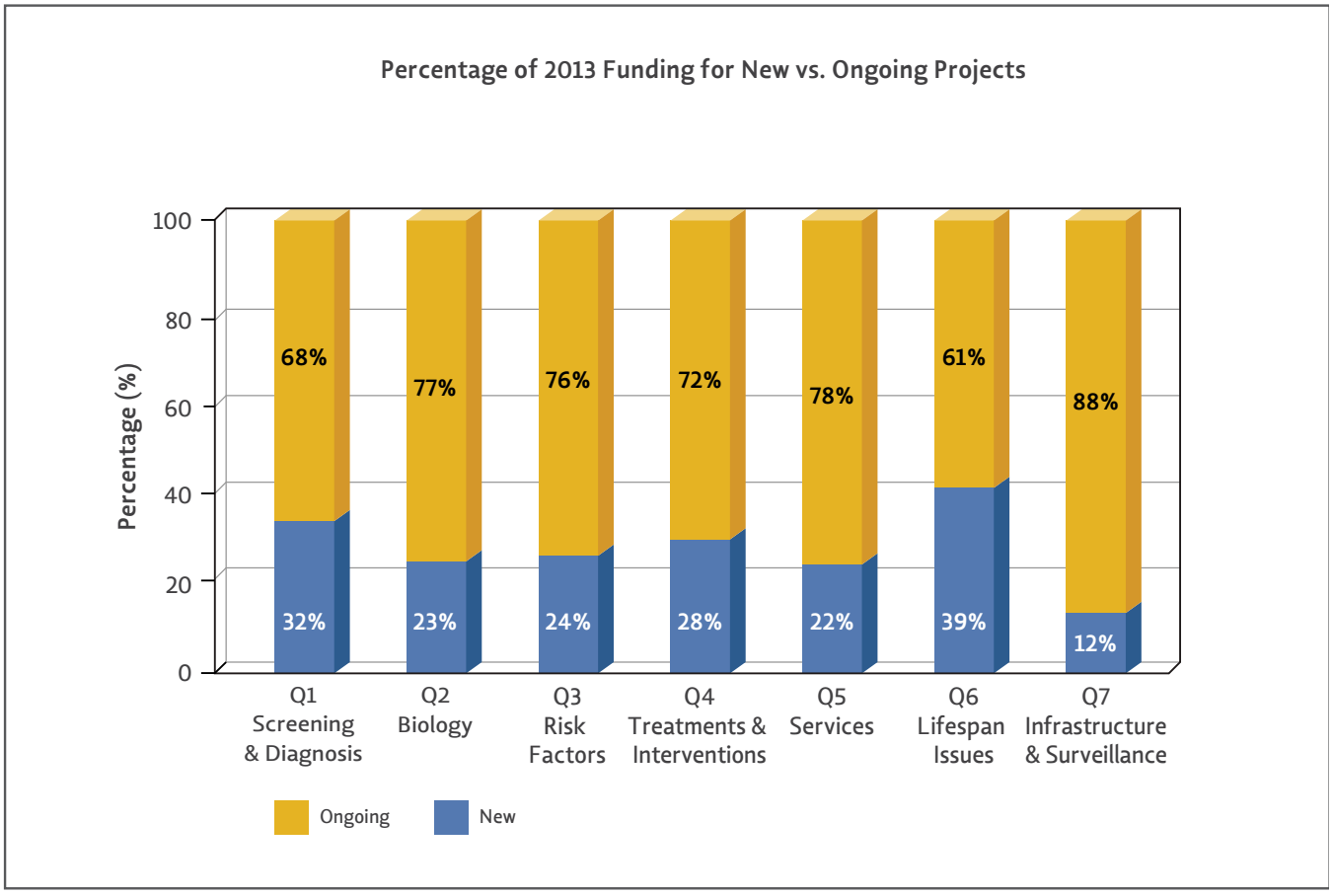


Figure 9. The percentages of ASD research funding going to new versus ongoing projects varies between *Strategic Plan* questions.

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

The Federal and private funders included in this *Portfolio Analysis Report* fund a wide range of autism-related research projects. As shown in **Figure 10**, Federal and private funders contributed to funding for each of the question areas in the *IACC Strategic Plan for ASD Research* in 2013. However, the proportions of Federal and private funding varies by question area, suggesting that some areas align more closely with Federal or private 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 services (Question 5) is largely supported by funding from Federal sources.

In addition to the variation in Federal and private support of research in each question area, the type of research represented in the portfolios of individual funders varies based on the mission of each individual agency or organization. **Figure 11** depicts the proportion of funded projects for each agency and organization for each of the seven question areas of the *IACC Strategic Plan*. **Figure 12** 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.

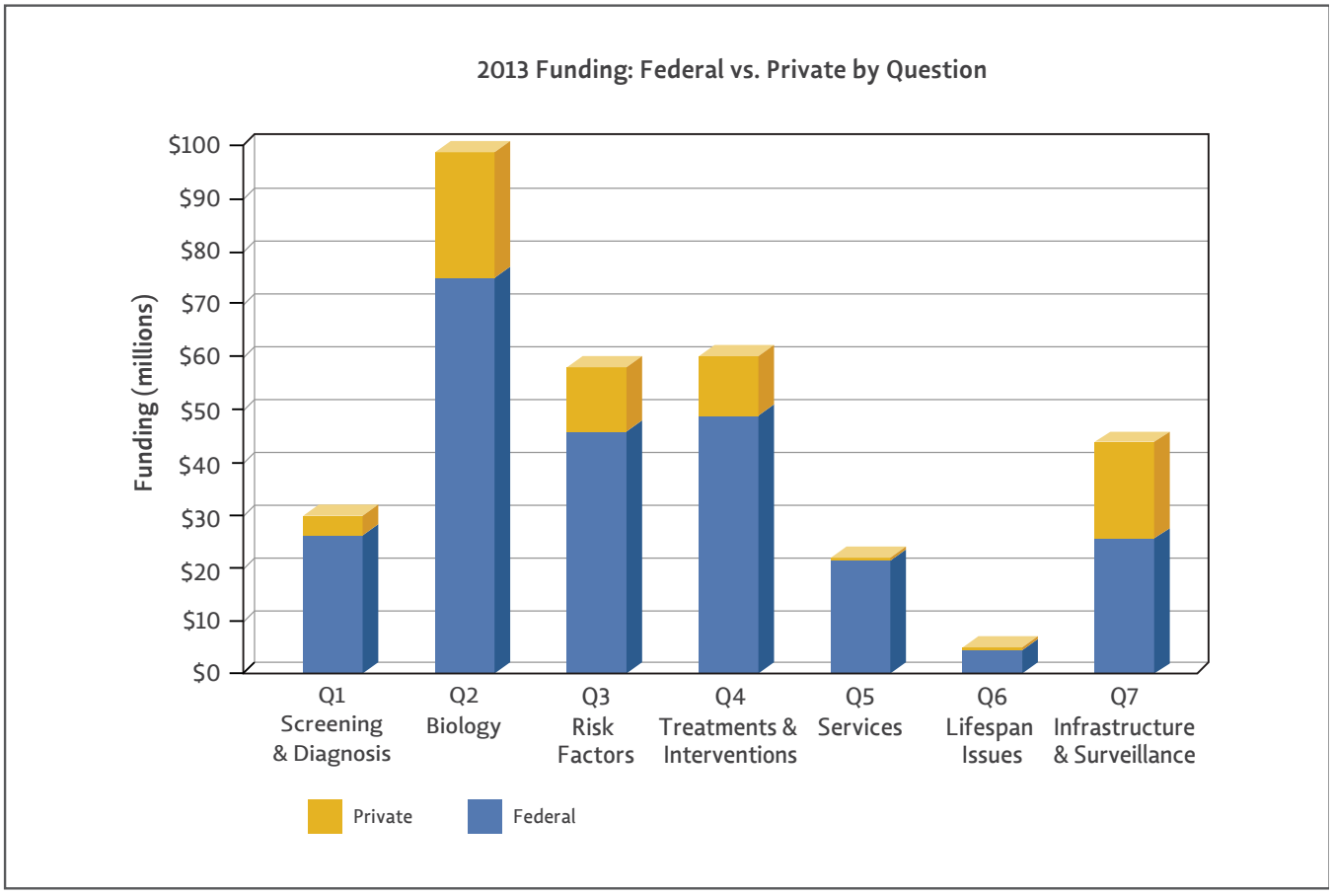


Figure 10. Federal and private funding was provided for each *Strategic Plan* question area in 2013, although the proportion of Federal vs. private funding varied between question areas.

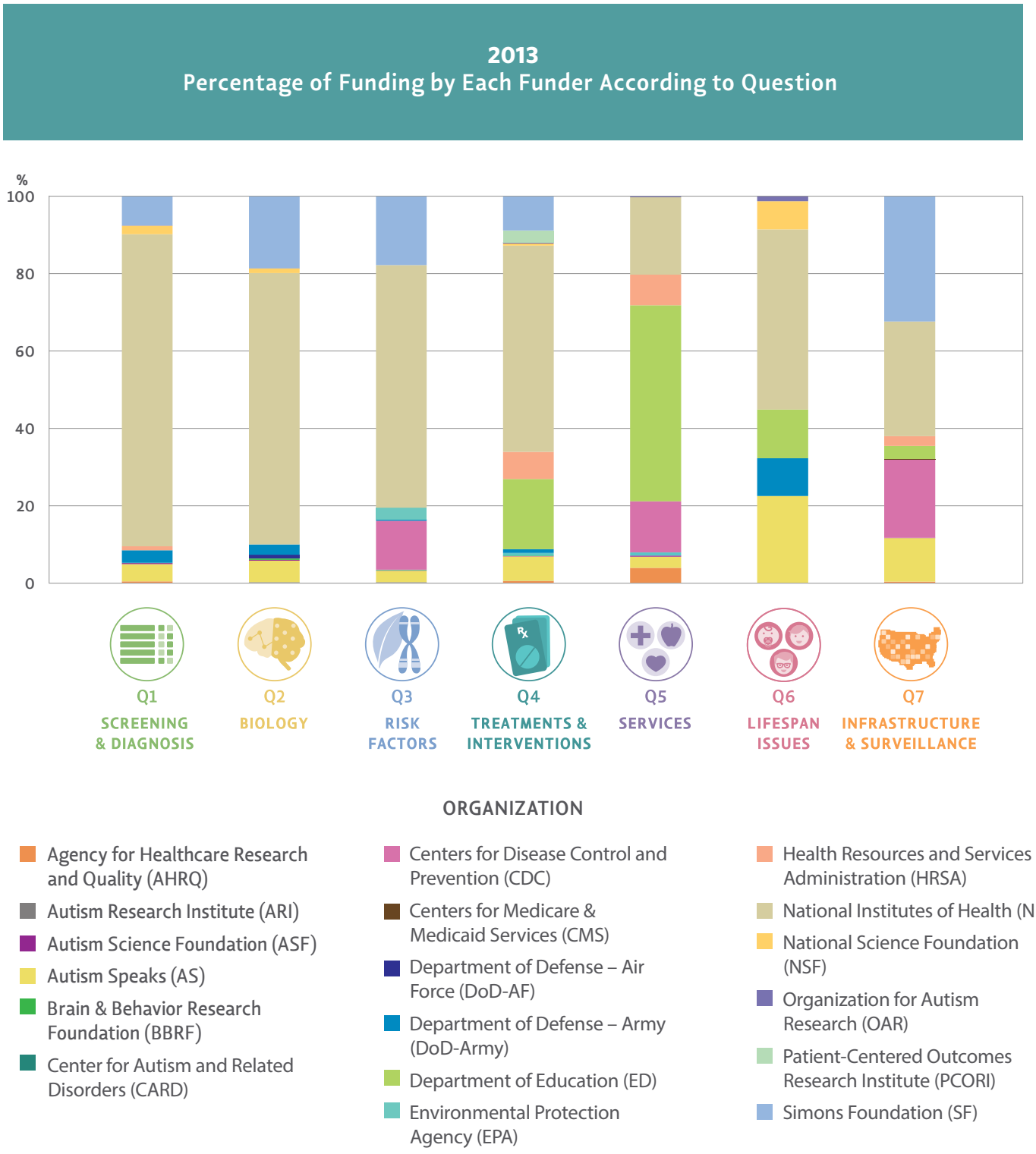


Figure 11. The proportion of each Federal agency and private organization's funding in the *Portfolio Analysis* organized by *IACC Strategic Plan* question for 2013. ACF was not included in this figure since they did not have any funding reported in 2013.

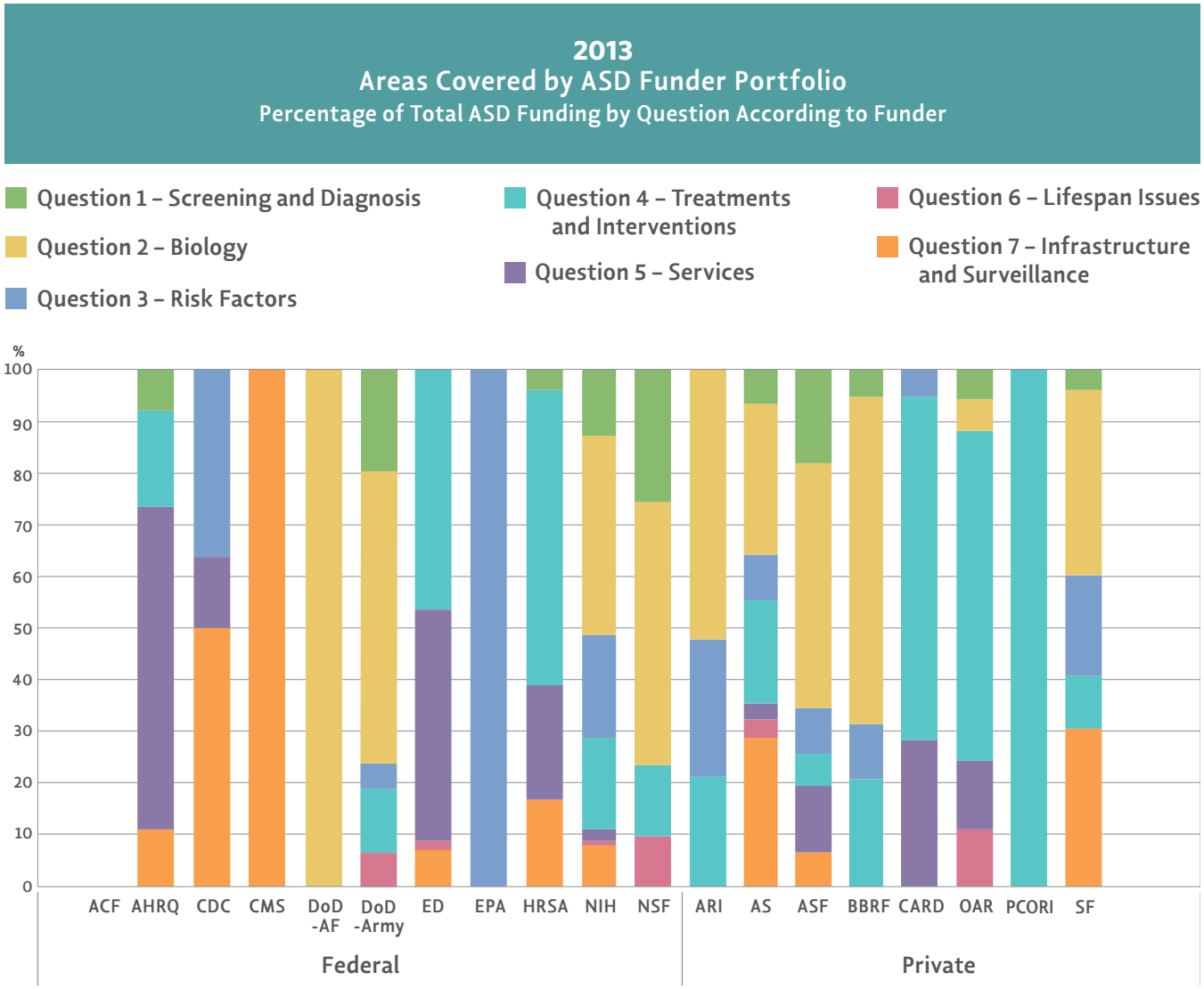


Figure 12. The portfolio of each Federal agency and private organization's autism-related projects by *Strategic Plan* question for 2013. Please note that this figure is based on funding amount from 2013. Thus, while funders may support additional areas of research, that may not be reflected in this particular year. Note that the Administration for Children and Families (ACF) had one active project, and therefore is included in the analysis, but the active project received no funding in 2013.

How did the research projects funded in 2013 align with the objectives in the *IACC Strategic Plan*?

The 78 *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 further research efforts. The 2013 autism research-related projects were matched with the best fitting research objective in the *Strategic Plan*, though in some cases, projects could only be assigned to a *Strategic Plan* question, and for the objective category, were assigned to Core/Other. The Core/Other category captures projects that may be related to crosscutting 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 projects 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 2013 project portfolios to determine the proportion of projects that fit within *Strategic Plan* objectives versus the proportion that did not fit within *Strategic Plan* objectives (**Figure 13**) showed that in 2013, 25% of the funding went to projects that were not specific to a particular objective. In addition, **Figure 14** shows that every question of the *Strategic Plan* included projects that were not specific to a particular objective (projects coded to Core/Other). Of all seven questions of the *Strategic Plan*, Question 2 contained the largest proportion of funding that did not align with any specific objective (47%). More detail on the types of research represented by projects that were categorized as Core/Other can be found in the subsequent chapters of this report that are focused on each *Strategic Plan* question.

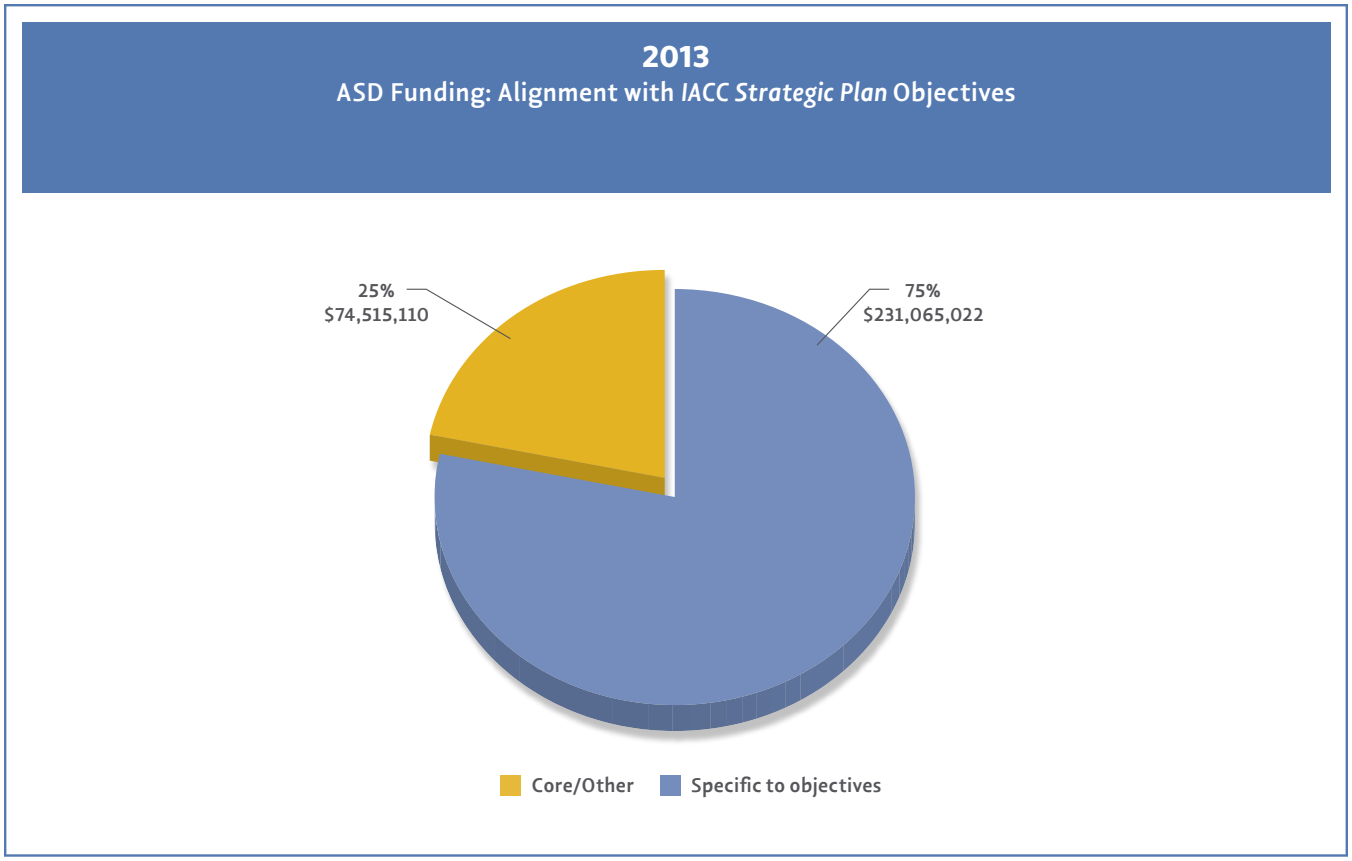
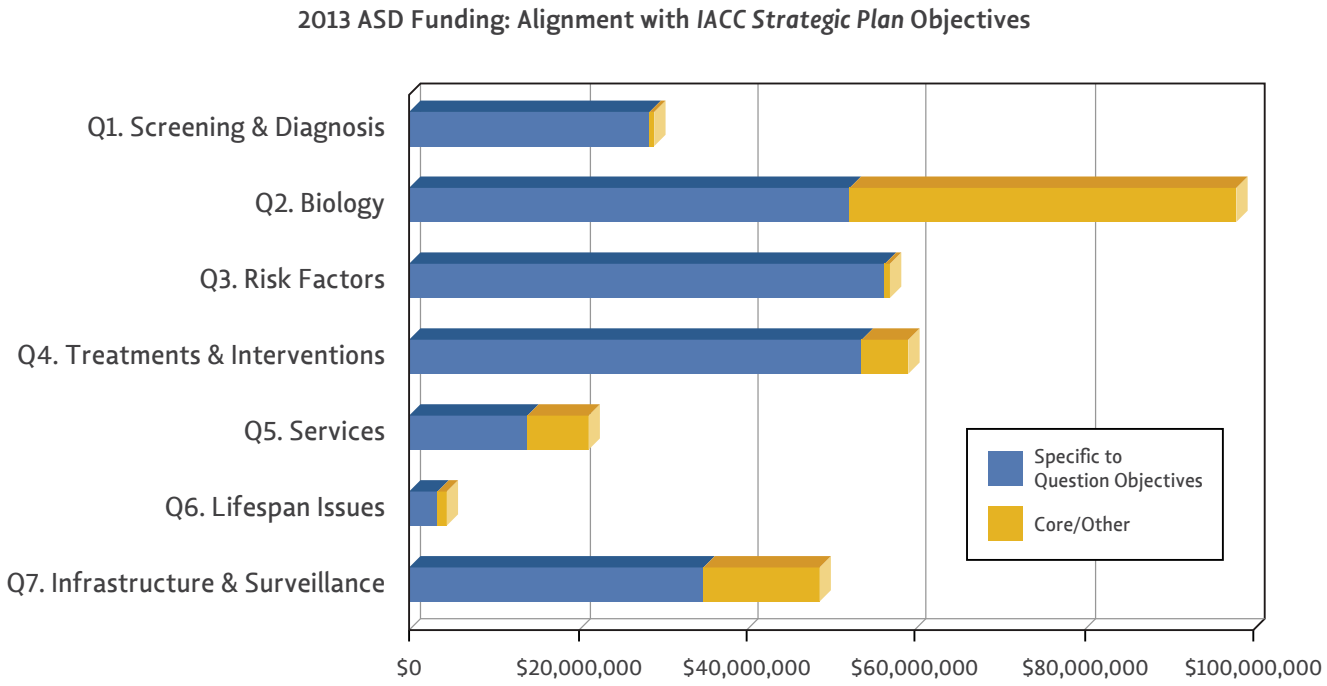


Figure 13. 25% of funding went to projects that were not specific to a particular *Strategic Plan* objective, and were designated Core/Other.



	Q1. Screening & Diagnosis	Q2. Biology	Q3. Risk Factors	Q4. Treatments & Interventions	Q5. Services	Q6. Lifespan Issues	Q7. Infrastructure & Surveillance
Specific to Question Objectives	$27,262,721	$51,072,288	$55,128,525	$52,351,118	$12,797,176	$2,062,646	$30,390,546
Core/Other	$389,937	$45,800,151	$537,826	$5,714,722	$7,250,109	$1,090,239	$13,732,127
Core/Other (%)	1%	47%	1%	10%	36%	35%	31%

Figure 14. 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 78 objectives in the *Strategic Plan* describe specific research priorities identified by the IACC, each with a goal date for initiation and a professional judgment estimate of the budget that may be required to accomplish the objective.[1] Each ASD project that received funding in 2013 was evaluated with respect to the 78 objectives in the *2011 IACC Strategic Plan for ASD Research*[2] in order to determine which *Strategic Plan* question and objective it fulfilled. Analysis of the full portfolio of Federal government and privately funded projects aligned with the *IACC Strategic Plan* objectives yielded information about the progress that has been made toward completion of the objectives in the *2011 Strategic Plan*. In 2013, this analysis indicated that of the 78 objectives in the *IACC Strategic Plan*, 95% (74 objectives) were underway or completed (green or yellow in the stoplight figure as explained below) (**Figure 15**). Further discussion of the progress toward achievement of individual *Strategic Plan* objectives is found in subsequent chapters of this report. The analysis also enabled assessment of areas of research where more work may be needed to achieve *Strategic Plan* objectives.

Upcoming chapters in this report give an overview of the progress on completing objectives in each question of the *Strategic Plan* in 2013. The overall progress for each question over the period from 2008-2013 is denoted by a stoplight figure at the end of each chapter. Within each stoplight figure, the number in the green light indicates the number of objectives that have been considered completed, the number in the yellow light indicates the number of objectives partially completed, and the number of objectives in the red light indicates the number of objectives where no progress has been documented through the portfolio analysis. Each of the chapters describing the progress in the seven *Strategic Plan* question areas also contains a table that provides information about the progress made toward completion of the *Strategic Plan* objectives over a six-year period from 2008 through 2013.

[1]Professional judgment budget estimates for each of the *IACC Strategic Plan* objectives were formulated by scientific and program experts in the field and provide an estimate of what it may cost to conduct each of the projects described. The IACC provided these budget recommendations as guidance to Federal agencies and partner organizations on the potential cost of conducting the recommended research. The IACC's role in research is advisory, and the Committee does not have its own research budget to conduct or support research.

[2]The *2011 IACC Strategic Plan* is the most recent update of the *Strategic Plan* where new objectives were added. The subsequent 2012 and 2013 Updates of the *Strategic Plan* did not include any edits to the objectives, therefore the objectives as described in the *2011 IACC Strategic Plan* were used to code the 2013 projects to specific objectives.

Summary of Overall Progress on *Strategic Plan* Objectives through 2013

Complete (Green) or Partially Complete (Yellow) Objectives

Inactive (Red) Objectives

	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Total	Percentage
Number of Complete Objectives	4	5	9	4	3	0	9	34	44%
Number of Partially Complete Objectives	4	4	6	8	6	8	4	40	51%
Number of Inactive Objectives	1	0	0	0	0	0	3	4	5%
Total	9	9	15	12	9	8	16	78	100%

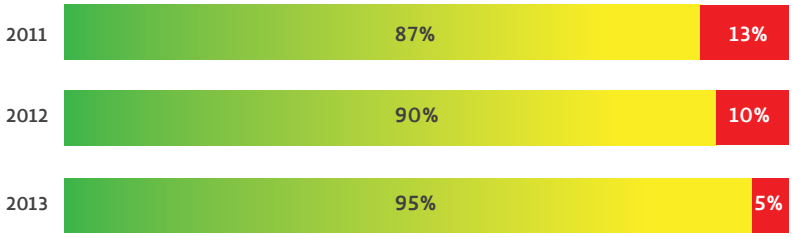


Figure 15. This figure provides the percentage of the total number of *IACC Strategic Plan* objectives that have been completed to date, based on an analysis of funded projects assigned to each of the *Strategic Plan's* 78 objectives. As of 2013, 95% of objectives were either complete or partially complete (had all or some of the required funded projects), with 5% of objectives having no activity/assigned projects.

ANALYSIS OF PROGRESS TOWARD *IACC STRATEGIC PLAN* OBJECTIVES BY RESEARCH AREA

QUESTION 1

SCREENING AND DIAGNOSIS

***ASPIRATIONAL GOAL:* CHILDREN AT RISK FOR ASD WILL BE IDENTIFIED THROUGH RELIABLE METHODS BEFORE ASD BEHAVIORAL CHARACTERISTICS FULLY MANIFEST.**

RESEARCH FOCUS OF QUESTION 1

Question 1 of the *IACC Strategic Plan* ("When should I be concerned?") pertains to the issues surrounding screening for and diagnosis of ASD, with a focus on early identification of children showing signs of ASD so that they have the opportunity to receive interventions and supports that will lead to improved outcomes. The objectives within this chapter of the *Strategic Plan* include research to develop biomarkers, screening tools, and diagnostic instruments to aid in early identification. Question 1 also includes research to better understand and overcome barriers to early identification, including efforts to increase access to health services, and to develop or adapt screening and diagnostic tools for use in a wide variety of community settings, at low cost, and in diverse populations. The Committee also prioritized the need for screening and diagnostic tools for use in adolescents and adults, and for improved measures that can be used to assess intervention and service needs. Projects addressing issues related to adult screening and diagnosis may be captured either within Question 1 or Question 6 of the *Strategic Plan* (Question 6 focuses on issues relevant to transitioning youth and adults on the autism spectrum).

In an effort to describe the research funded in Question 1 in 2013, a word cloud was generated using the project titles listed under this question research area (**Figure 16**). 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 funded in Question 1.

Figure 16. Word cloud representing themes in Question 1 project titles.

ANALYSIS OF 2013 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 9% ($27.7 million) of the total ASD research supported by Federal and private funders in 2013. The number of projects assigned to Question 1 totaled 127 projects, which was 10% of all projects included in the portfolio. The largest funders of research pertaining to Question 1 are the National Institutes of Health, Simons Foundation, and Autism Speaks. Progress made in Question 1 is measured through nine objectives. **Figure 17** provides a detailed overview of each objective's total funding in 2013 as well as the number of projects assigned to each objective.

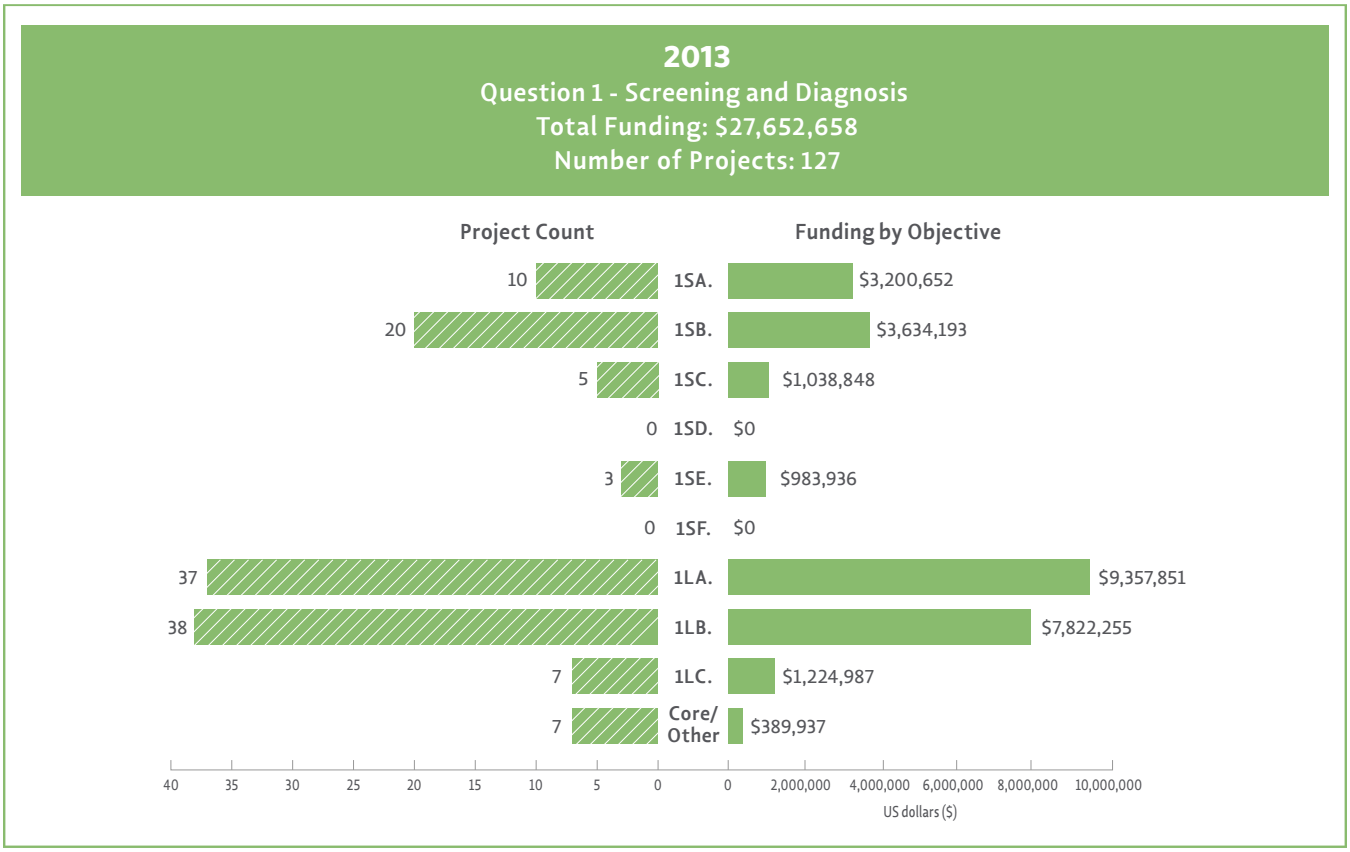


Figure 17. Question 1 objectives broken down by their funding and project count.

In 2013, four Question 1 objectives achieved their recommended annualized funding target, three partially achieved their annualized funding target, and two had no active projects or funding. As was the case in 2011 and 2012, the Question 1 objective receiving the most funding in 2013 was 1.L.A, which focuses on identifying biomarkers for ASD; it received 34% ($9.4 million) of the Question 1 funding in 2013. This was followed by Objective 1.L.B, which supports the development of behavioral and biological measures for diagnosis and risk assessment, accounting for 28% ($7.8 million) of Question 1 overall funding. Objectives 1.L.A and 1.L.B had the largest amount of projects as well. All other objectives received less than 15% of Question 1 funding in 2013, and only 1% of Question 1 funding went to projects categorized as Core/Other, which are projects not specific to Question 1 objectives. Studies to understand the impact of early diagnosis on choice of intervention and outcomes (1.S.D) did not have any activity in 2013. Although Objective 1.S.F was also not funded in 2013, it was already considered completed due to workshops convened in previous years. **Table 4** lists all the objectives and their progress to date.

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 neared $27.7 million in 2013 and were divided into four subcategories: **Diagnostic and screening tools; Early signs and biomarkers; Intermediate phenotypes/Subgroups**; and **Symptomology** (**Figure 18**).

Of the four subcategories related to Question 1 (Screening and Diagnosis), in 2013 the largest proportion of funding was devoted to identifying **Early signs and biomarkers** for ASD (43%), which contained 56 projects. 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. The development of **Diagnostic and screening tools** (32%), which accounted for 36 projects, was the second largest research investment in Question 1. This was followed by research characterizing **Symptomology** (14%; 25 projects). The subcategory receiving the lowest proportion of funding included research on identifying/characterizing **Intermediate phenotypes/Subgroups** of people with ASD (12%) with only 10 projects.

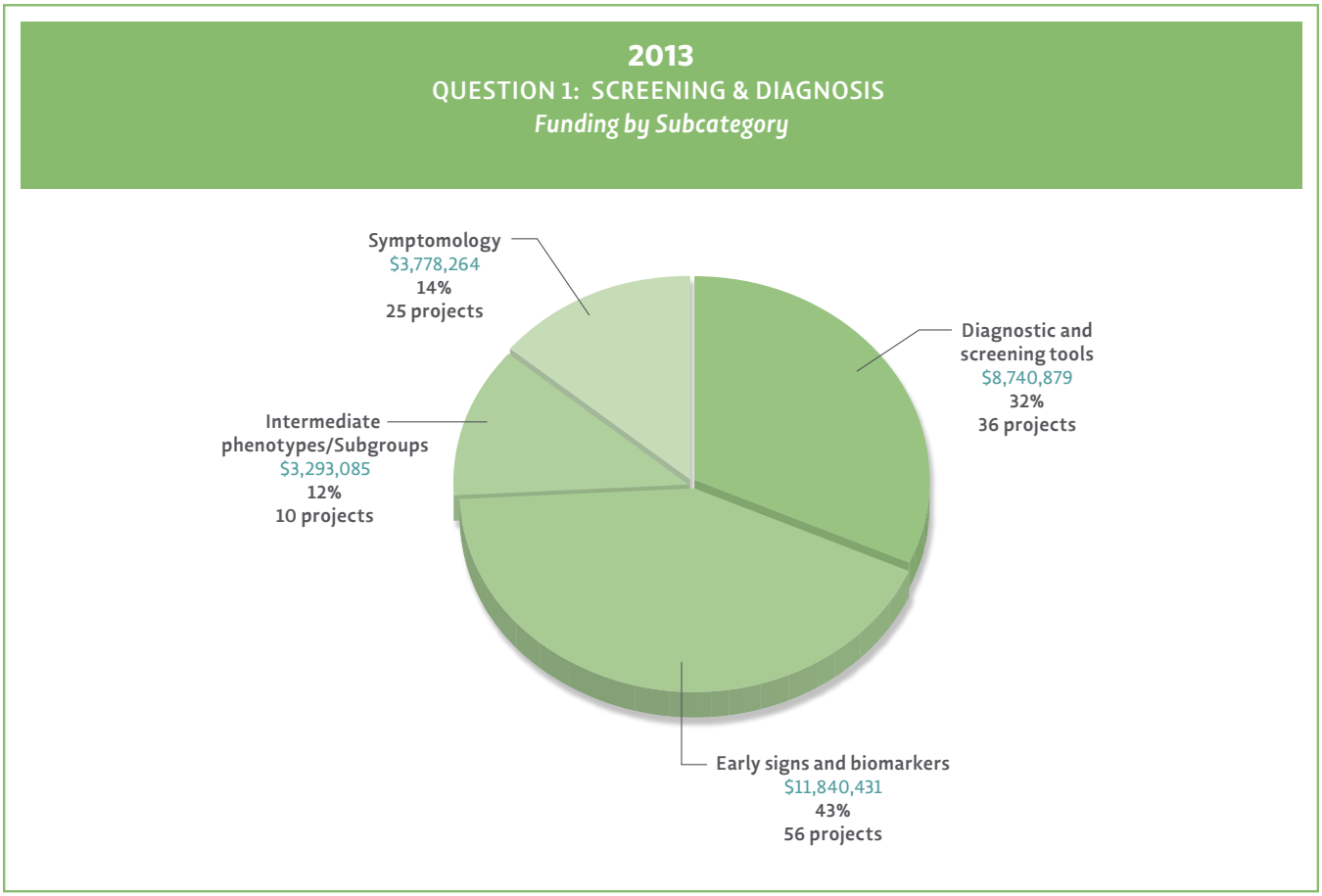


Figure 18. Question 1 funding by subcategory in 2013.

PROGRESS MADE ON QUESTION 1 FROM 2008-2013

Figure 19 shows the trend in Question 1 funding over time. When considering annual funding for Question 1 from 2008-2013, 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.

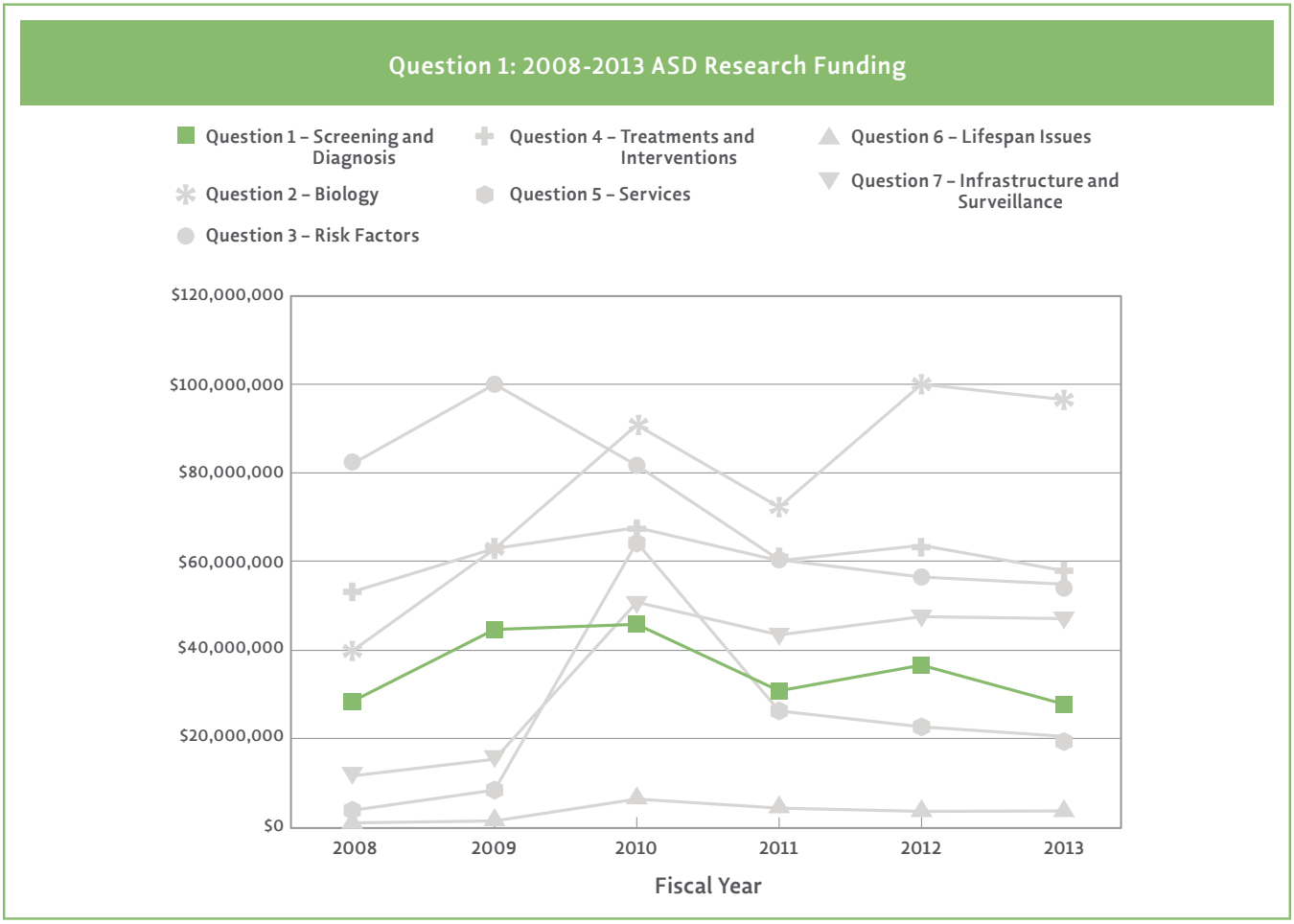


Figure 19. Question 1 ASD research funding from 2008-2013. Funding for Question 1 was moderate and stayed relatively flat over the six-year span.

PROGRESS MADE ON QUESTION 1 OBJECTIVES FROM 2008-2013

After six years of funding, four of the Question 1 objectives were considered completed in terms of the recommended amount of total funding invested. Of the remaining Question 1 objectives, partial progress was made on four, while no progress was documented through the portfolio analysis data collection on one objective (**Figure 20**). Although funding for all but two of the Question 1 objectives grew in 2013, it was not enough to change the overall status of any of the Question 1 objectives from what was reported in 2012. **Table 4** provides an overview of progress made on all nine of the research objectives within Question 1 over the period from 2008-2013.

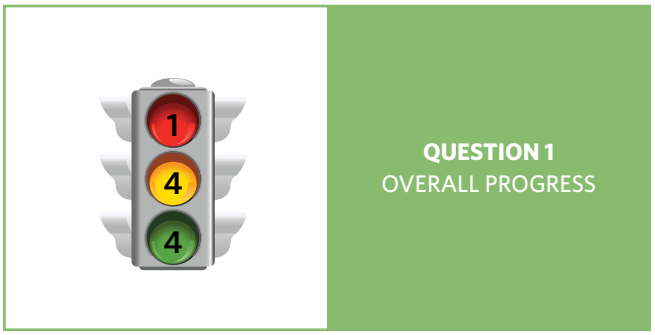


Figure 20. Overall status of progress for the nine Question 1 objectives.

Question 1: When Should I Be Concerned?

IACC Strategic Plan Objectives	Funding						
Year	2008	2009	2010	2011	2012	2013	Total
Develop, with existing tools, at least one efficient diagnostic instrument (i.e., briefer, less time intensive) that is valid in diverse populations for use in large-scale studies by 2011.	1.1 $75,000 2 projects	1.S.A $4,728,120 15 projects	1.S.A $4,963,192 15 projects	1.S.A $2,387,955 8 projects	1.S.A $2,214,544 8 projects	1.S.A $3,200,652 10 projects	$17,569,463
	IACC Recommended Budget: $5,300,000 over 2 years						
Validate and improve the sensitivity and specificity of new or existing screening and diagnostic tools, including comparative studies of general developmental screening versus autism-specific screening tools, in both high-risk and population-based samples, including those from resource-poor international settings and those that are diverse in terms of age, socioeconomic status, race, ethnicity, gender, characteristics of ASD, and general level of functioning by 2012.	1.2 $1,246,922 8 projects	1.S.B $3,973,712 11 projects	1.S.B $2,443,557 11 projects	1.S.B $1,120,246 10 projects	1.S.B $2,255,138 13 projects	1.S.B $3,634,193 20 projects	$14,673,768
	IACC Recommended Budget: $5,400,000 over 3 years						
Conduct at least three studies to identify reasons for the health disparities in accessing early screening and diagnosis services, including identification of barriers to implementation of and access to screening, diagnosis, referral, and early intervention services among diverse populations, as defined by socioeconomic status, race, ethnicity, and gender of the child, by 2012.	N/A	1.S.C $139,072 1 project	1.S.C $0 0 projects	1.S.C $28,000 1 project	1.S.C $629,521 3 projects	1.S.C $1,038,848 5 projects	$1,835,441
		IACC Recommended Budget: $2,000,000 over 2 years					
Conduct at least two studies to understand the impact of early diagnosis on choice of intervention and outcomes by 2015.	N/A	1.S.D $0 0 projects	1.S.D $0 0 projects	1.S.D $0 0 projects	1.S.D $0 0 projects	1.S.D $0 0 projects	$0
		IACC Recommended Budget: $6,000,000 over 5 years					
Conduct at least one study to determine the positive predictive value and clinical utility (e.g., prediction of co-occurring conditions, family planning) of chromosomal microarray genetic testing for detecting genetic diagnoses for ASD in a clinical setting by 2012.	N/A	N/A	1.S.E $2,180,042 3 projects	1.S.E $690,019 1 project	1.S.E $1,273,122 4 projects	1.S.E $983,936 3 projects	$5,127,119
			IACC Recommended Budget: $9,600,000 over 5 years				
Convene a workshop to examine the ethical, legal, and social implications of ASD research by 2011. The workshop should define possible approaches for conducting future studies of ethical, legal, and social implications of ASD research, taking into consideration how these types of issues have been approached in related medical conditions.	N/A	N/A	1.S.F $0 0 projects	1.S.F* $71,489 1 project	1.S.F* $0 0 projects	1.S.F* $0 0 projects	$71,489
			IACC Recommended Budget: $35,000 over 1 year **completed in 2011*				

Question 1: Multiyear Funding Table, see Appendix C for a color-coding key and further details.

Question 1: When Should I Be Concerned?

IACC Strategic Plan Objectives	Funding						
Year	**2008**	**2009**	**2010**	**2011**	**2012**	**2013**	**Total**
Identify behavioral and biological markers that separately, or in combination, accurately identify, before age 2, one or more subtypes of children at risk for developing ASD, and evaluate whether these risk markers or profiles can improve early identification through heightened developmental monitoring and screening by 2014.	**1.3** $2,885,940 14 projects	**1.L.A** $16,465,034 43 projects	**1.L.A** $13,270,045 45 projects	**1.L.A** $12,416,466 43 projects	**1.L.A** $12,894,621 40 projects	**1. L.A** $9,357,851 37 projects	**$67,289,957**
	IACC Recommended Budget: $33,300,000 over 5 years						
Develop at least five measures of behavioral and/or biological heterogeneity in children or adults with ASD, beyond variation in intellectual disability, that clearly relate to etiology and risk, treatment response and/or outcome by 2015.	**1.4** $5,773,203 18 projects	**1.L.B** $8,760,010 34 projects	**1.L.B** $15,228,060 52 projects	**1.L.B** $9,376,400 42 projects	**1.L.B** $12,813,396 39 projects	**1.L.B** $7,822,255 38 projects	**$59,773,324**
	IACC Recommended Budget: $71,100,000 over 5 years						
Identify and develop measures to assess at least three "continuous dimensions" (i.e., social reciprocity, communication disorders, and repetitive/restrictive behaviors) of ASD symptoms and severity that can be used by practitioners and/or families to assess response to intervention for people with ASD across the lifespan by 2016.	**1.5** $912,159 2 projects	**1.L.C** $861,069 6 projects	**1.L.C** $3,893,622 22 projects	**1.L.C** $2,353,440 15 projects	**1.L.C** $2,600,028 15 projects	**1.L.C** $1,224,987 7 projects	**$11,845,305**
	IACC Recommended Budget: $18,500,000 over 5 years						
Not specific to any objective	**1. Core/ Other Activities** $18,229,985 63 projects	**1. Core/ Other Activities** $9,766,926 37 projects	**1. Core/ Other Activities** $3,643,562 18 projects	**1. Core/ Other Activities** $2,310,877 16 projects	**1. Core/ Other Activities** $2,175,749 13 projects	**1. Core/ Other Activities** $389,937 7 projects	**$36,517,036**
Total funding for Question 1	**$29,123,209** 107 projects	**$44,693,943** 147 projects	**$45,622,080** 166 projects	**$30,754,892** 137 projects	**$36,856,119** 135 projects	**$27,652,659** 127 projects	**$214,702,902**

Question 1: Multiyear Funding Table, see Appendix C for a color-coding key and further details.

Table 4. Multiyear funding table for Question 1.

QUESTION 2
BIOLOGY

***ASPIRATIONAL GOAL:* DISCOVER HOW ASD AFFECTS DEVELOPMENT, WHICH WILL LEAD TO TARGETED AND PERSONALIZED INTERVENTIONS.**

RESEARCH FOCUS OF QUESTION 2

Question 2 ("How can I understand what is happening?") addresses the underlying biology of ASD. Research in this field focuses on identifying the biological differences and mechanisms in early development and throughout life that contribute to ASD, as well as the characterization of the behavioral and cognitive aspects of ASD. Projects range from basic neuroscience using cellular and animal models to clinical studies. Taken together, 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.

A word cloud was created using the project titles listed under Question 2 to provide a visual representation of the research funded in 2013 (**Figure 21**). 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 funded in Question 2.

Figure 21. Word cloud representing themes in Question 2 project titles.

ANALYSIS OF 2013 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 2013. Following similar trends as previous years, research on the biology of ASD (Question 2) comprised 32% of total funding ($96.9 million) and 37% of all projects (476 projects). The agencies and organizations with the largest investments in Question 2 are the National Institutes of Health, Simons Foundation, and Autism Speaks. All nine objectives in Question 2 experienced at least some progress in 2013. **Figure 22** provides a detailed overview of each objective's total funding in 2013 as well as the number of projects assigned to each objective.

The majority of projects that were categorized under this question did not fit into any of the specific Question 2 research objectives and were assigned as Question 2 Core/Other ($45.8 million, 47%), similar to what was reported in previous years. As is described in the previous section of this report, projects designated as Core/Other correspond to research areas that were already established and/or well-funded at the time the *Strategic Plan* was developed, as well as areas of emerging science that may not have been captured in the *Strategic Plan* objectives. The next largest portion of funding went to Objective 2.S.D ($18.6 million, 19%), which focuses on the underlying biology of genetic conditions related to ASD, such as Rett Syndrome and Fragile X Syndrome. Objective 2.S.G, which includes projects investigating a link between specific genotypes and functional or structural phenotypes, had the next greatest portion of funding ($12.6 million, 13%). Across portfolio analyses, Objectives 2.S.D and 2.S.G. have received the largest portion of Question 2 funding consistently since 2009. **Table 5** lists all the objectives and their progress to date.

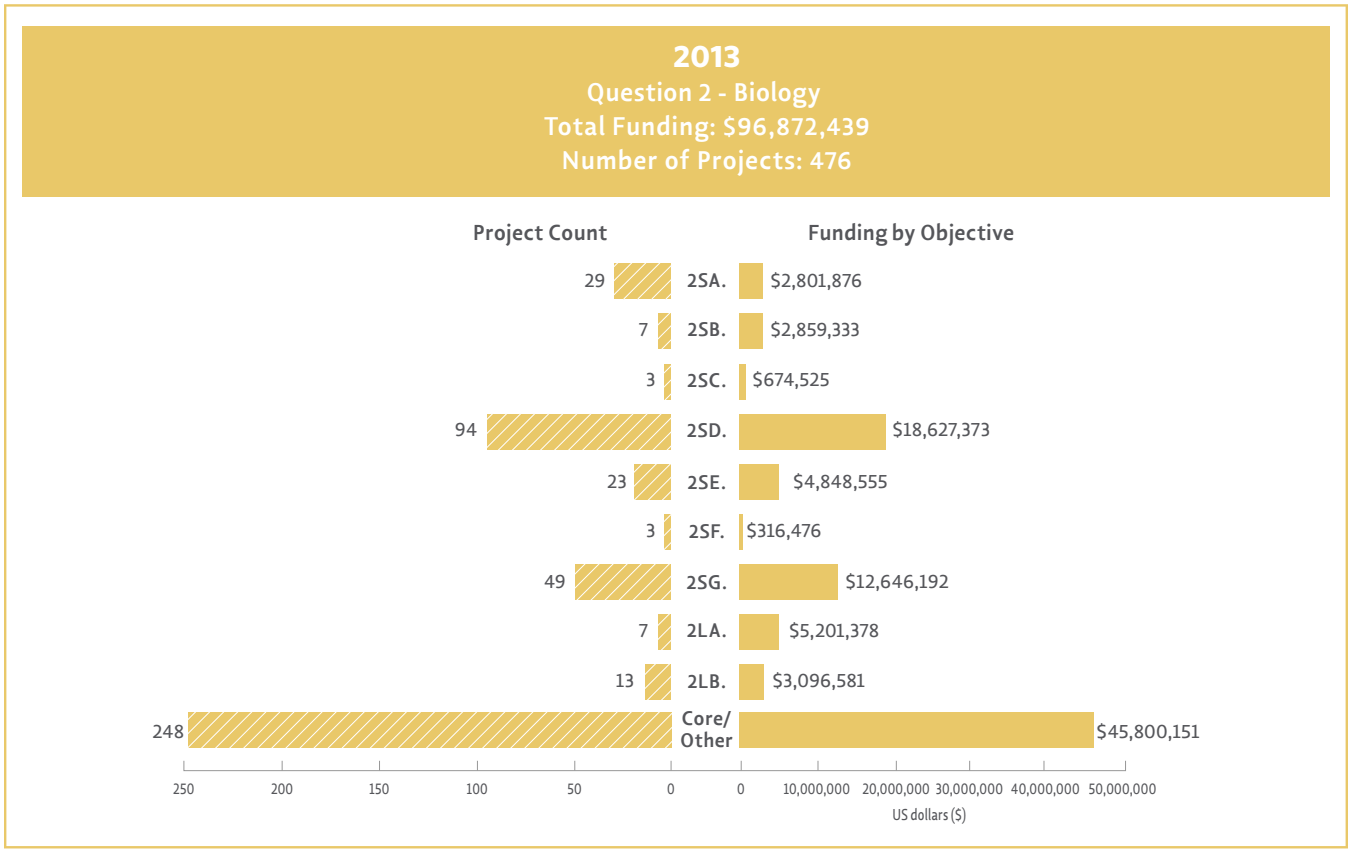


Figure 22. Question 2 objectives broken down by their funding and project count.

QUESTION 2 SUBCATEGORY ANALYSIS

Due to the large proportion of research in Question 2 that could not be assigned to a particular objective, the subcategory analysis was particularly useful 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, which received approximately $96.9 million of total funding in 2013, 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 23**).

As was the case in 2011 and 2012, the Question 2 subcategory with the largest portion of funding was **Molecular pathways** (32%; 170 projects), which includes investigating systems of genes, proteins, and other molecules that are involved in ASD and related disorders. Research exploring the **Neural systems** (18%) was the second largest investment and included 82 projects. The third largest subcategory focused on projects aiming to identify **Subgroups/Biosignatures** (17%; 62 projects). Research into the **Developmental trajectory** of ASD, including longitudinal studies that follow social, behavioral, and physical development over time accounted for 9% of Question 2 funding and included 21 projects. Projects investigating **Sensory and motor function** and **Co-occurring conditions** both accounted for roughly 5% of funding and included 26 and 25 projects, respectively. **Cognitive studies** accounted for 4% of ASD funding and included 23 projects. Research in **Computational science** (18 projects), **Immune/Metabolic pathways** (31 projects), and **Neuropathology** (18 projects) all accounted for about 3% of funding in 2013.

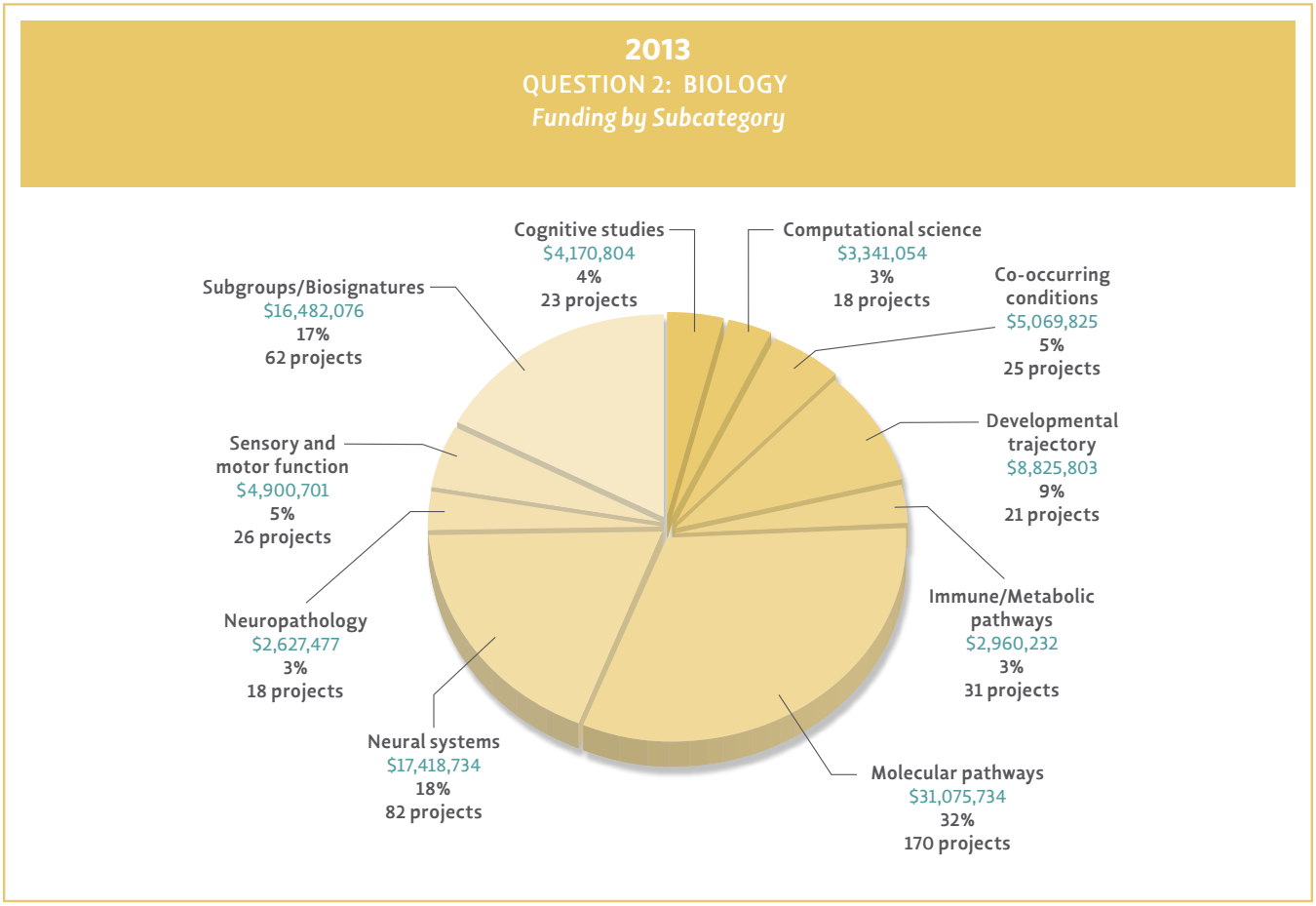


Figure 23. Question 2 funding by subcategory in 2013.

PROGRESS MADE ON QUESTION 2 FROM 2008-2013

Figure 24 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 2008-2013, portfolio analysis data showed that funding levels for this question potentially seemed to plateau somewhat in recent years, despite having undergone a significant increase from 2008-2013.

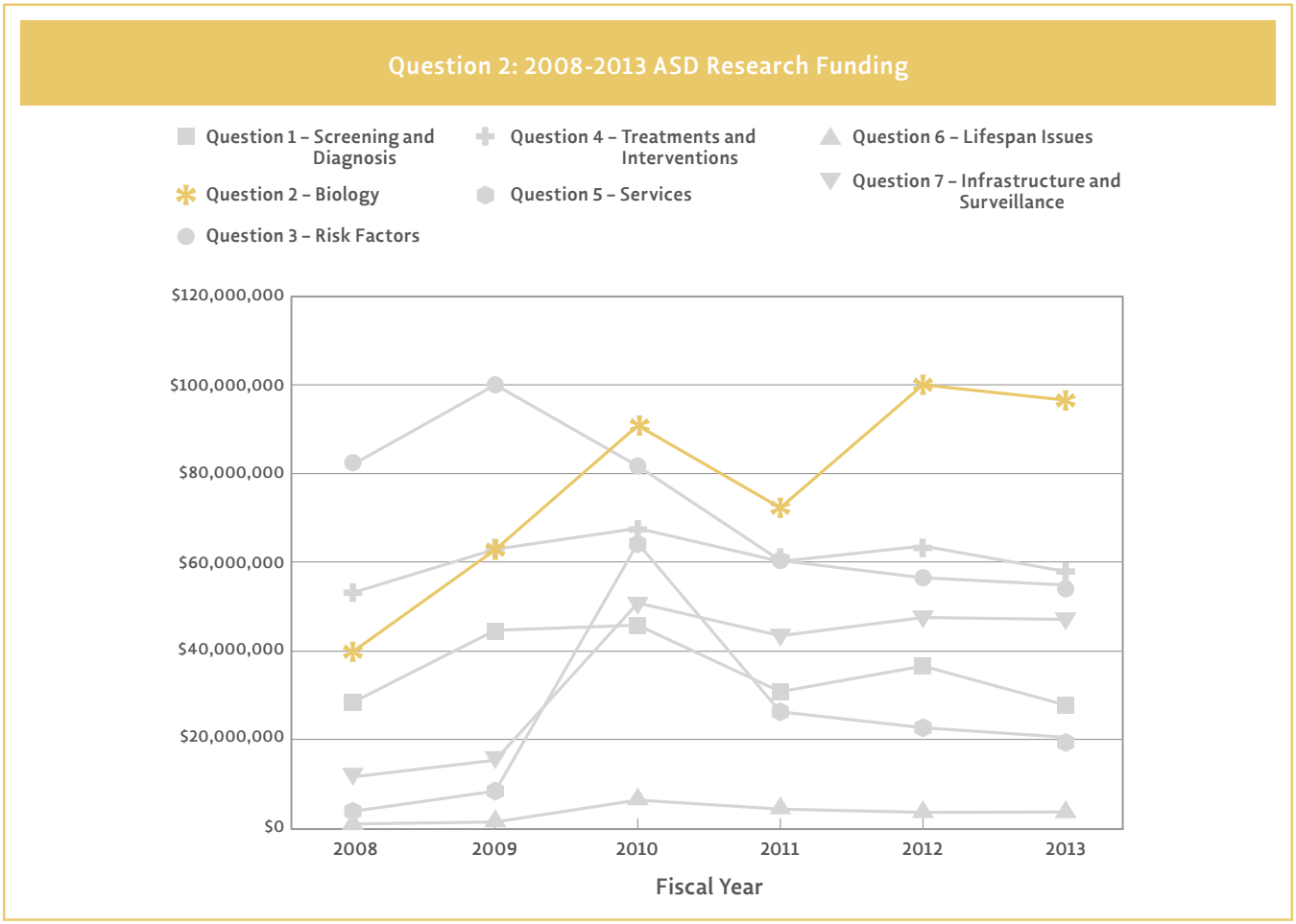


Figure 24. Question 2 ASD research funding from 2008-2013. Funding for Question 2 rapidly increased, and then leveled off, over the six-year span.

PROGRESS MADE ON QUESTION 2 OBJECTIVES FROM 2008-2013

As of 2013, five of the nine Question 2 objectives were considered completed in terms of meeting their overall budget recommendations, while four objectives were considered partially completed (**Figure 25**). The funding received for Question 2 Objective 2.S.C in 2013 was enough to change its overall status from "partially completed" as of 2012 to "completed" as of 2013. Objective 2.S.C addressed the need to increase awareness among the autism spectrum community about the importance of brain and tissue donation to further basic research. **Table 5** provides a snapshot of progress made on all nine of the research objectives within Question 2 over the period from 2008-2013.

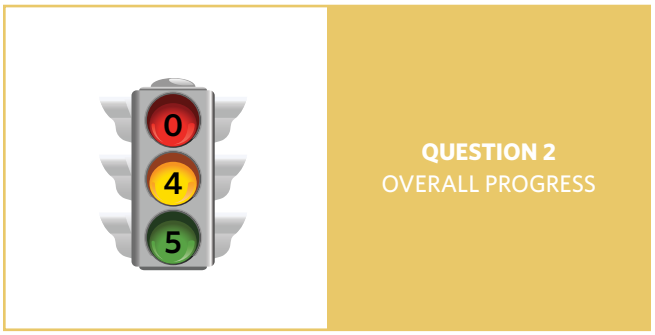


Figure 25. Overall status of progress for the nine Question 2 objectives.

Question 2: How Can I Understand What is Happening?

IACC Strategic Plan Objectives	Funding						
Year	**2008**	**2009**	**2010**	**2011**	**2012**	**2013**	**Total**
Support at least four research projects to identify mechanisms of fever, metabolic and/or immune system interactions with the central nervous system that may influence ASD during prenatal-postnatal life by 2010 (Fever studies to be started by 2012).	**2.2** $3,377,568 18 projects	**2.S.A** $3,584,634 30 projects	**2.S.A** $4,972,407 37 projects	**2.S.A** $2,013,417 25 projects	**2.S.A** $3,049,827 26 projects	**2.S.A** $2,801,876 29 projects	**$19,799,729**
	IACC Recommended Budget: $9,800,000 over 4 years						
Launch three studies that specifically focus on the neurodevelopment of females with ASD, spanning basic to clinical research on sex differences by 2011.	**2.3** $0 0 projects	**2.S.B** $1,370,107 5 projects	**2.S.B** $1,096,678 5 projects	**2.S.B** $150,000 1 project	**2.S.B** $3,239,998 5 projects	**2.S.B** $2,859,333 7 projects	**$8,716,116**
	IACC Recommended Budget: $8,900,000 over 5 years						
Identify ways to increase awareness among the autism spectrum community of the potential value of brain and tissue donation to further basic research by 2011.	**2.4** $0 0 projects	**2.S.C** $726,911 2 projects	**2.S.C** $17,000 1 project	**2.S.C** $22,000 1 project	**2.S.C** $90,120 1 project	**2.S.C** $674,525 5 projects	**$1,530,556**
	IACC Recommended Budget: $1,400,000 over 2 years						
Launch three studies that target improved understanding of the underlying biological pathways of genetic conditions related to autism (e.g., Fragile X, Rett syndrome, tuberous sclerosis complex) and how these conditions inform risk assessment and individualized intervention by 2012.	N/A	**2.S.D** $9,171,542 48 projects	**2.S.D** $13,162,905 57 projects	**2.S.D** $12,360,956 64 projects	**2.S.D** $18,452,242 83 projects	**2.S.D** $18,627,373 94 projects	**$71,775,018**
		IACC Recommended Budget: $9,000,000 over 5 years					
Launch three studies that target the underlying biological mechanisms of co-occurring conditions with autism, including seizures/epilepsy, sleep disorders, wandering/elopement behavior, and familial autoimmune disorders, by 2012.	N/A	**2.S.E** $3,893,300 11 projects	**2.S.E** $4,611,058 14 projects	**2.S.E** $4,807,760 23 projects	**2.S.E** $3,218,960 22 projects	**2.S.E** $4,848,555 23 projects	**$21,379,633**
		IACC Recommended Budget: $9,000,000 over 5 years					
Launch two studies that focus on prospective characterization of children with reported regression to investigate potential risk factors by 2012.	N/A	**2.S.F** $0 0 projects	**2.S.F** $401,595 2 projects	**2.S.F** $339,709 3 projects	**2.S.F** $251,830 2 projects	**2.S.F** $316,476 3 projects	**$1,309,610**
		IACC Recommended Budget: $4,500,000 over 5 years					
Support five studies that associate specific genotypes with functional or structural phenotypes, including behavioral and medical phenotypes (e.g., nonverbal individuals with ASD and those with cognitive impairments) by 2015.	N/A	**2.S.G** $5,903,875 21 projects	**2.S.G** $9,149,672 39 projects	**2.S.G** $11,105,408 45 projects	**2.S.G** $15,618,073 44 projects	**2.S.G** $12,646,192 49 projects	**$54,423,220**
		IACC Recommended Budget: $22,600,000 over 5 years					
Complete a large-scale, multidisciplinary, collaborative project that longitudinally and comprehensively examines how the biological, clinical, and developmental profiles of individuals, with a special emphasis on females, youths, and adults with ASD, change over time as compared to typically developing people by 2020.	**2.5** $8,523,806 49 projects	**2.L.A** $2,721,384 6 projects	**2.L.A** $2,283,875 6 projects	**2.L.A** $972,559 5 projects	**2.L.A** $6,160,017 9 projects	**2.L.A** $5,201,378 7 projects	**$25,863,019**
	IACC Recommended Budget: $126,200,000 over 12 years						

Question 2: Multiyear Funding Table, see Appendix C for a color-coding key and further details.

Question 2: How Can I Understand What is Happening?

IACC Strategic Plan Objectives	Funding						
Year	**2008**	**2009**	**2010**	**2011**	**2012**	**2013**	**Total**
Launch at least three studies that evaluate the applicability of ASD phenotype and/or biological signature findings for performing diagnosis, risk assessment, or clinical intervention by 2015.	N/A	**2.L.B** $1,532,262 16 projects	**2.L.B** $450,271 2 projects	**2.L.B** $324,241 4 projects	**2.L.B** $1,321,632 8 projects	**2.L.B** $3,096,581 13 projects	**$6,724,987**
	IACC Recommended Budget: $7,200,000 over 5 years						
Not specific to any objective	**2. Core/ Other Activities** $23,701,450 133 projects	**2. Core/ Other Activities** $34,348,933 163 projects	**2. Core/ Other Activities** $55,114,888 246 projects	**2. Core/ Other Activities** $41,127,339 228 projects	**2. Core/ Other Activities** $48,851,715 261 projects	**2. Core/ Other Activities** $45,800,151 248 projects	**$248,944,476**
Total funding for Question 2†	**$40,621,403** 202 projects	**$63,252,948** 302 projects	**$91,260,349** 409 projects	**$73,223,388** 399 projects	**$100,254,414** 461 projects	**$96,872,439** 476 projects	**$465,484,942***

Question 2: Multiyear Funding Table, see Appendix C for a color-coding key and further details.

*This total reflects all funding for projects aligned to current objectives in the *2011 IACC Strategic Plan* and incorporates funding for projects that may have been coded differently in previous versions of the *Plan.*

†The totals reflect the funding and projects coded to this Question of the *Strategic Plan* in the particular year indicated at the top of the column. When reading each column vertically, please note that the projects and funding associated with each objective for 2008 may not add up to the total at the bottom of the column; this is due to revisions of the *Strategic Plan* that caused some objectives to be shifted to other Questions under the *Plan.* The projects and funding associated with these reclassified objectives are now reflected under the Question in which they appear in the *2011 Strategic Plan.*

Table 5. Multiyear funding table for Question 2.

QUESTION 3

RISK FACTORS

***ASPIRATIONAL GOAL:* CAUSES OF ASD WILL BE DISCOVERED THAT INFORM PROGNOSIS AND TREATMENTS AND LEAD TO PREVENTION/PREEMPTION OF THE CHALLENGES AND DISABILITIES OF ASD.**

RESEARCH FOCUS OF QUESTION 3

Question 3 ("What caused this to happen and can it be prevented?") focuses on the risk factors associated with the development of ASD. Research related to Question 3 looks at the role of genetics, epigenetics, and the environment in the development of ASD, as well as the interactions between risk factors. Question 3 objectives address topics such as the need to develop improved approaches to study environmental exposures and gene-environment interactions, and to explore the potential roles of the microbiome and epigenetics on etiology. Also included are studies of risk factors and protective factors (factors that may protect an individual from developing ASD, even in the presence of other risk factors).

To describe the research funded in Question 3 in 2013, a word cloud was generated using the project titles listed under this question (**Figure 26**). 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 funded in Question 3.

Figure 26. Word cloud representing themes in Question 3 project titles.

ANALYSIS OF 2013 QUESTION 3 PORTFOLIO

In 2013, research on risk factors associated with ASD (Question 3) accounted for $55.7 million (18%) of total ASD research funding and included 145 projects (11% of all projects). The largest funders of Question 3 are the National Institutes of Health, Simons Foundation, and the Centers for Disease Control and Prevention.

Question 3 consists of 15 objectives, all but one of which experienced at least some level of activity in 2013 (the objective that had no activity was completed in a previous year). **Figure 27** provides a detailed overview of each objective's total funding in 2013 as well as the number of projects assigned to each objective.

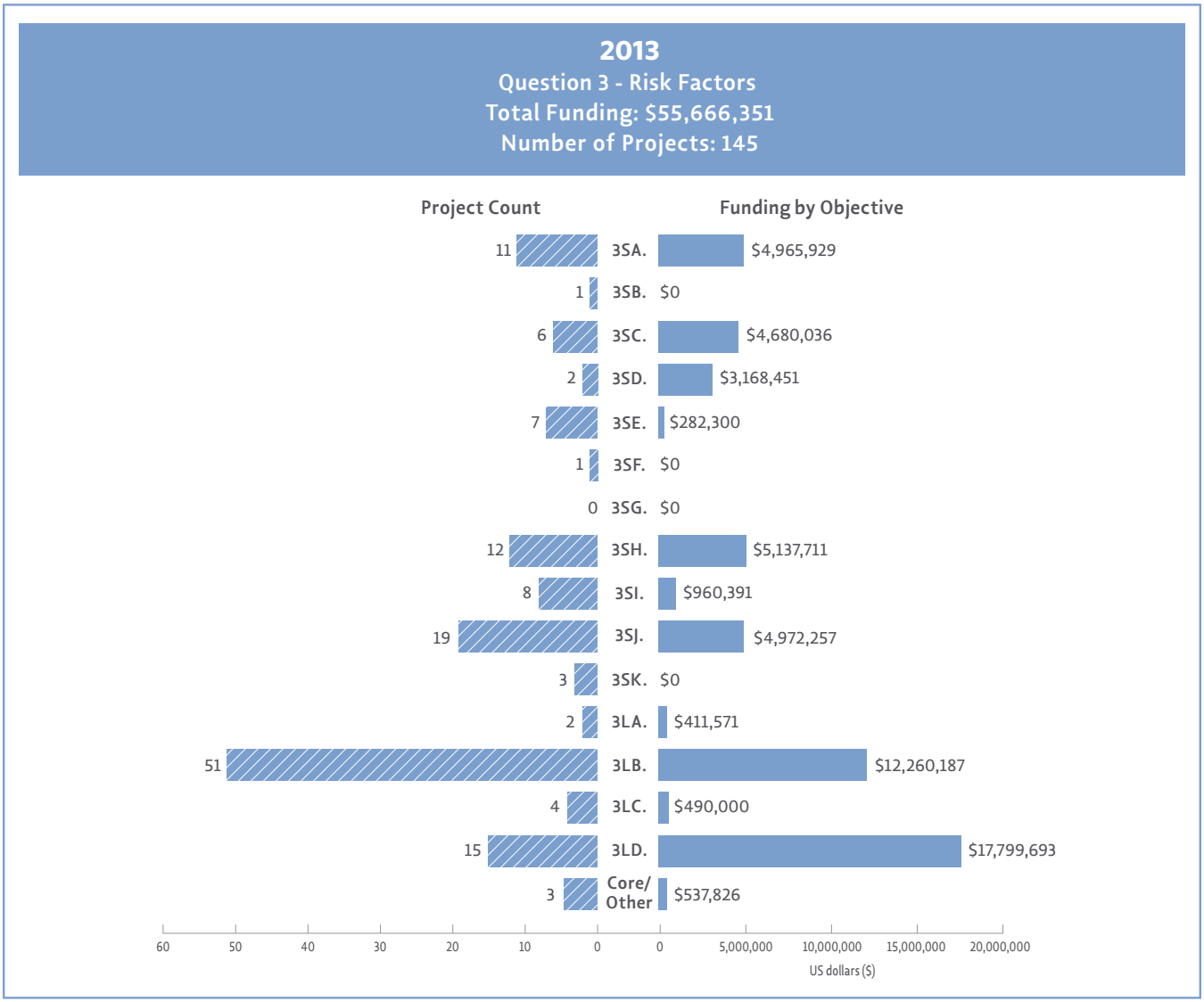


Figure 27. Question 3 objectives broken down by their funding and project count.

Objective 3.L.D received the largest proportion of funding in 2013, which supports multiple sites within a large-scale study that collects data on environmental factors before and during pregnancy to assess any potential risk factors ($17.8 million, 32%). This was followed by the objective that had previously received the largest proportion of Question 3 funding in 2011 and 2012, 3.L.B ($12.3 million; 22%), which identifies genetic risk factors for ASD. All of the other objectives in Question 3 received a smaller portion of funding and number of projects. In addition, objective 3.S.G was completed by a workshop convened by the National Institute of Environmental Health Sciences (NIEHS) in 2011; objectives 3.S.B, 3.S.F, and 3.S.K did not receive any new funding in 2013 though they still had active projects. **Table 6** lists all the objectives and their progress to date.

QUESTION 3 SUBCATEGORY ANALYSIS

Projects in Question 3, which made up nearly $55.7 million of total funding in 2013, 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 28**).

In 2013, investigating the role of environmental risk factors, genetic susceptibility, and/or the context of human physiology (**Gene-Environment**) accounted for the majority of research funding (43%). Studies focused on **Genetic risk factors** were the second largest research

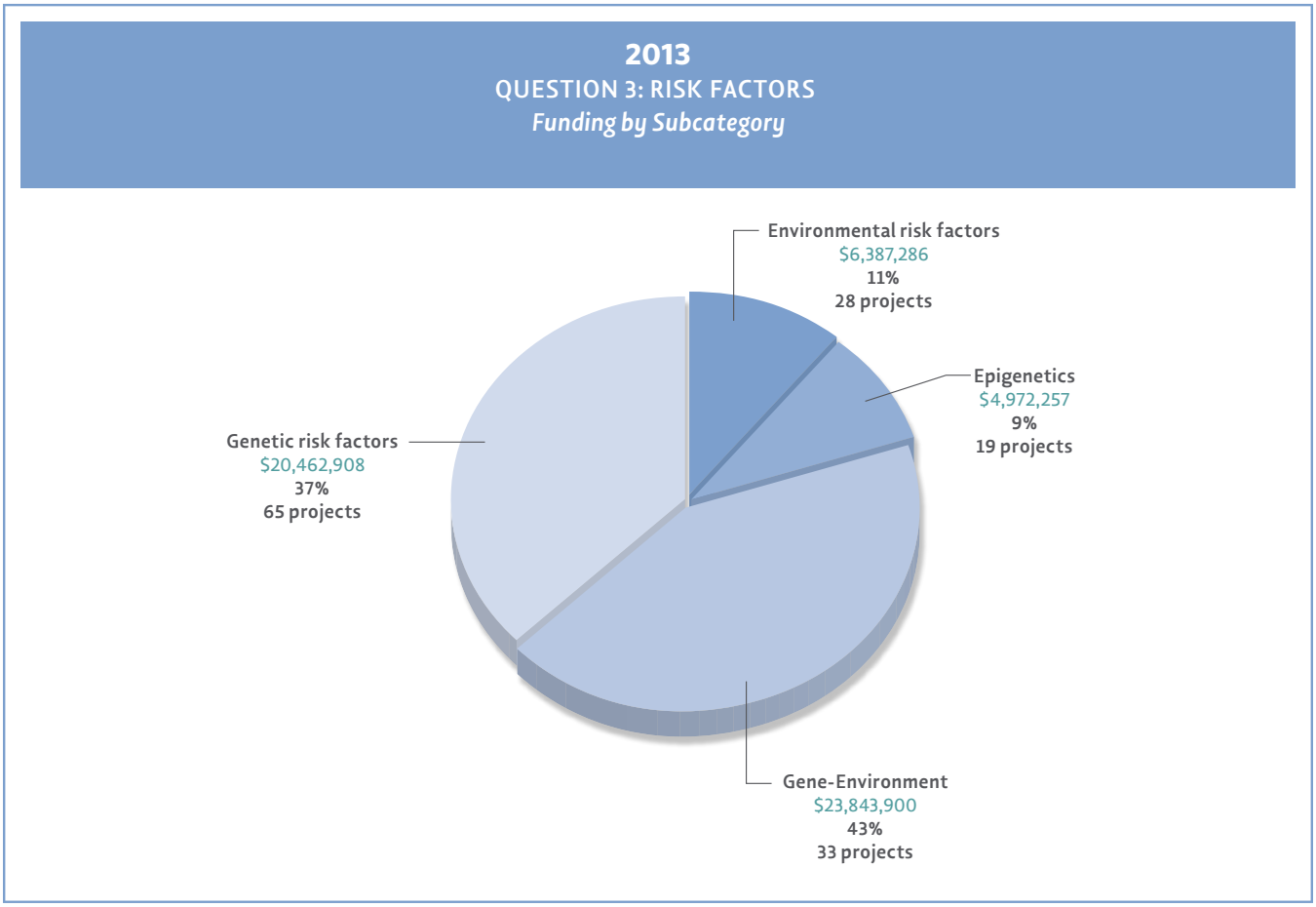


Figure 28. Question 3 funding by subcategory in 2013.

investment (37%). Projects considering only **Environmental risk factors** received 11% of funding for projects within Question 3. Projects on **Epigenetics** received 9% of funding, which included studies investigating DNA modifications and exploring altered gene expression due to environmental influences.

PROGRESS MADE ON QUESTION 3 FROM 2008-2013

Figure 29 shows the trend in Question 3 funding over time. While research on risk factors remained supported at high levels over the six-year period compared to some of the other question areas, the overall trend showed an initial increase followed by a gradual decrease and then a general leveling off of the annual funding level from 2011-2013.

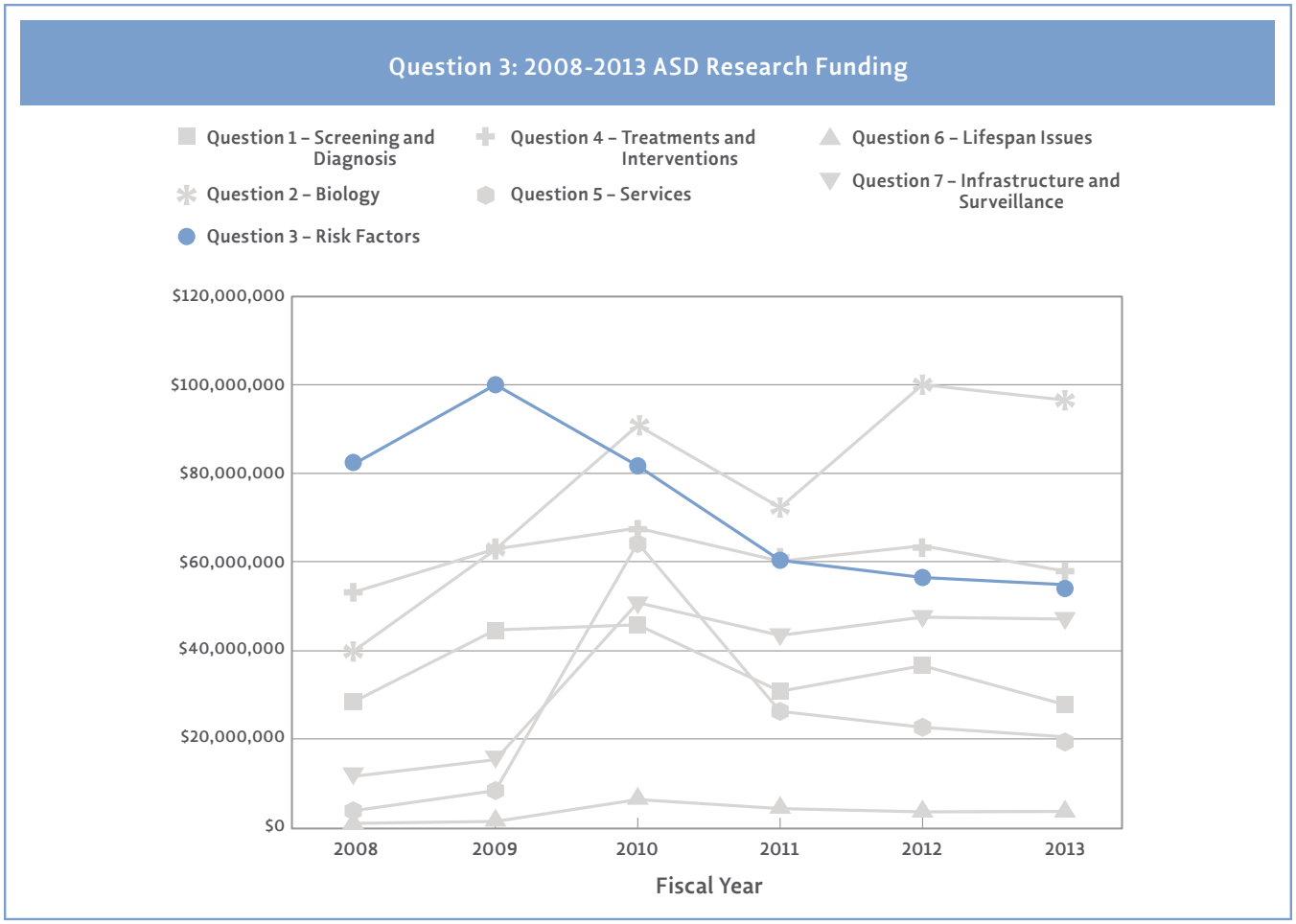


Figure 29. Question 3 ASD research funding from 2008-2013. Funding for Question 3 initially showed a steady decrease, and then leveled off, over the six-year span.

PROGRESS MADE ON QUESTION 3 OBJECTIVES FROM 2008-2013

As of 2013, nine of Question 3's objectives were considered completed, while the remaining six were partially completed based on the total recommended budget levels (**Figure 30**). Of the nine completed objectives, five changed from an overall "partially completed" status as of 2012 to a "completed" status as of 2013. The objectives that have been newly completed in 2013 include: 3.S.C, which expands existing large case-control and other studies to enhance targeted gene-environment research; 3.S.D, which enhances existing case-control studies to enroll racially and ethnically diverse populations affected by ASD; 3.S.H, which includes studies to inform understanding of environmental risk factors for ASD in pregnancy and the early postnatal period; 3.S.I, which includes studies on microbiome differences between individuals with ASD; and 3.S.J, which includes studies focused on the role of epigenetics in the etiology of ASD. **Table 6** provides a snapshot of progress made on all 15 of the research objectives within Question 3 over the period from 2008-2013.

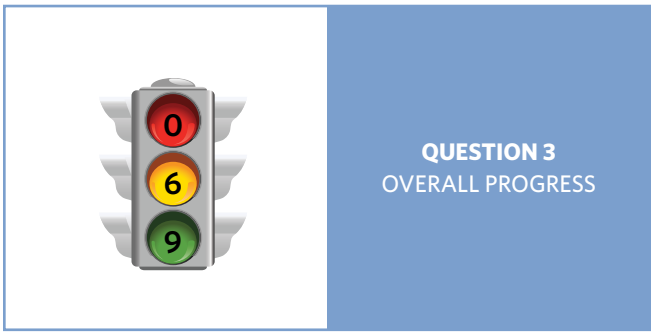


Figure 30. Overall status of progress for the 15 Question 3 objectives.

Question 3: What Caused This To Happen And Can It Be Prevented?

IACC Strategic Plan Objectives	Funding						
Year	**2008**	**2009**	**2010**	**2011**	**2012**	**2013**	**Total**
Coordinate and implement the inclusion of approximately 20,000 subjects for genome-wide association studies, as well as a sample of 1,200 for sequencing studies to examine more than 50 candidate genes by 2011. Studies should investigate factors contributing to phenotypic variation across individuals who share an identified genetic variant and stratify subjects according to behavioral, cognitive, and clinical features.	3.2 $4,065,392 14 projects	3.S.A $13,926,663 11 projects	3.S.A $16,688,932 14 projects	3.S.A $2,207,214 7 projects	3.S.A $1,699,432 6 projects	3.S.A $4,965,929 11 projects	$43,553,562
	IACC Recommended Budget: $43,700,000 over 4 years						
Within the highest-priority categories of exposures for ASD, identify and standardize at least three measures for identifying markers of environmental exposure in biospecimens by 2011.	3.3 $713,227 4 projects	3.S.B $0 0 projects	3.S.B $0 0 projects	3.S.B $0 0 projects	3.S.B $100,000 1 project	3.S.B $0 1 project	$813,227
	IACC Recommended Budget: $3,500,000 over 3 years						
Initiate efforts to expand existing large case-control and other studies to enhance capabilities for targeted gene-environment research by 2011.	3.4 $4,703,867 4 projects	3.S.C $8,033,454 9 projects	3.S.C $4,824,779 8 projects	3.S.C $5,714,408 10 projects	3.S.C $3,626,803 9 projects	3.S.C $4,680,036 6 projects	$31,583,347
	IACC Recommended Budget: $27,800,000 over 5 years						
Enhance existing case-control studies to enroll racially and ethnically diverse populations affected by ASD by 2011.	3.5 $84,628 2 projects	3.S.D $103,827 3 projects	3.S.D $0 0 projects	3.S.D $0 0 projects	3.S.D $0 0 projects	3.S.D $3,168,451 2 projects	$3,356,906
	IACC Recommended Budget: $3,300,000 over 5 years						
Support at least two studies to determine if there are subpopulations that are more susceptible to environmental exposures (e.g., immune challenges related to infections, vaccinations, or underlying autoimmune problems) by 2012.	N/A	3.S.E $1,739,200 13 projects	3.S.E $1,162,679 10 projects	3.S.E $419,215 5 projects	3.S.E $287,218 5 projects	3.S.E $282,300 7 projects	$3,890,612
	IACC Recommended Budget: $8,000,000 over 2 years						
Initiate studies on at least 10 environmental factors identified in the recommendations from the 2007 IOM report "Autism and the Environment: Challenges and Opportunities for Research" as potential causes of ASD by 2012.	3.1 $7,600,673 19 projects	3.S.F $2,952,960 14 projects	3.S.F $166,362 5 projects	3.S.F $0 3 projects	3.S.F $75,000 1 project	3.S.F $0 1 project	$10,794,995
	IACC Recommended Budget: $56,000,000 over 2 years						
Convene a workshop that explores the usefulness of bioinformatic approaches to identify environmental risks for ASD by 2011.	N/A	N/A	3.S.G $0 0 projects	3.S.G* $46,991 1 project	3.S.G* $0 0 projects	3.S.G* $0 0 projects	$46,991
	IACC Recommended Budget: $35,000 over 1 year **This objective was completed in 2011*						

Question 3: Multiyear Funding Table, see Appendix C for a color-coding key and further details.

Question 3: What Caused This To Happen And Can It Be Prevented?

IACC Strategic Plan Objectives	Funding						
Year	2008	2009	2010	2011	2012	2013	Total
Support at least three studies of special populations or use existing databases to inform our understanding of environmental risk factors for ASD in pregnancy and the early postnatal period by 2012. Such studies could include: • Comparisons of populations differing in geography, gender, ethnic background, exposure history (e.g., prematurity, maternal infection, nutritional deficiencies, toxins), and migration patterns; and • Comparisons of phenotype (e.g., cytokine profiles), in children with and without a history of autistic regression, adverse events following immunization (such as fever and seizures), and mitochondrial impairment. These studies may also include comparisons of phenotype between children with regressive ASD and their siblings. Emphasis on environmental factors that influence prenatal and early postnatal development is particularly of high priority. Epidemiological studies should pay special attention to include racially and ethnically diverse populations.	N/A	N/A	**3.S.H** $1,527,866 13 projects	**3.S.H** $4,657,095 16 projects	**3.S.H** $4,096,317 13 projects	**3.S.H** $5,137,711 12 projects	**$15,418,989**
			IACC Recommended Budget: $12,000,000 over 5 years				
Support at least two studies that examine potential differences in the microbiome of individuals with ASD versus comparison groups by 2012.	N/A	N/A	**3.S.I** $53,960 3 projects	**3.S.I** $439,971 4 projects	**3.S.I** $255,332 6 projects	**3.S.I** $960,391 8 projects	**$1,709,654**
			IACC Recommended Budget: $1,000,000 over 2 years				
Support at least three studies that focus on the role of epigenetics in the etiology of ASD, including studies that include assays to measure DNA methylations and histone modifications and those exploring how exposures may act on maternal or paternal genomes via epigenetic mechanisms to alter gene expression, by 2012.	N/A	N/A	**3.S.J** $5,072,389 15 projects	**3.S.J** $5,341,237 19 projects	**3.S.J** $6,122,724 22 projects	**3.S.J** $4,972,257 19 projects	**$21,508,607**
			IACC Recommended Budget: $20,000,000 over 5 years				
Support two studies and a workshop that facilitate the development of vertebrate and invertebrate model systems for the exploration of environmental risks and their interaction with gender and genetic susceptibilities for ASD by 2012.	N/A	N/A	**3.S.K** $733,922 5 projects	**3.S.K** $463,841 3 projects	**3.S.K** $90,000 3 projects	**3.S.K** $0 3 projects	**$1,287,763**
			IACC Recommended Budget: $1,535,000 over 3 years				
Conduct a multi-site study of the subsequent pregnancies of 1,000 women with a child with ASD to assess the impact of environmental factors in a period most relevant to the progression of ASD by 2014.	**3.7** $2,742,999 1 project	**3.L.A** $3,740,812 2 projects	**3.L.A** $2,971,093 2 projects	**3.L.A** $2,864,377 1 project	**3.L.A** $2,875,202 2 projects	**3.L.A** $411,571 2 projects	**$15,606,054**
			IACC Recommended Budget: $11,100,000 over 5 years				

Question 3: Multiyear Funding Table, see Appendix C for a color-coding key and further details.

Question 3: What Caused This To Happen And Can It Be Prevented?

IACC Strategic Plan Objectives	Funding						
Year	**2008**	**2009**	**2010**	**2011**	**2012**	**2013**	**Total**
Identify genetic risk factors in at least 50% of people with ASD by 2014.	**3.8** $37,043,410 83 projects	**3.L.B** $49,905,587 79 projects	**3.L.B** $34,432,884 60 projects	**3.L.B** $25,383,346 59 projects	**3.L.B** $23,041,231 74 projects	**3.L.B** $12,260,187 51 projects	**$182,066,645**
	IACC Recommended Budget: $33,900,000 over 6 years						
Determine the effect of at least five environmental factors on the risk for subtypes of ASD in the prenatal and early postnatal period of development by 2015.	**3.6** $1,803,628 13 projects	**3.L.C** $1,992,228 10 projects	**3.L.C** $820,320 10 projects	**3.L.C** $379,913 5 projects	**3.L.C** $353,000 5 projects	**3.L.C** $490,000 4 projects	**$5,839,089**
	IACC Recommended Budget: $25,100,000 over 7 years						
Support ancillary studies within one or more large-scale, population-based surveillance and epidemiological studies, including U.S. populations, to collect data on environmental factors during preconception, and during prenatal and early postnatal development, as well as genetic data, that could be pooled (as needed) to analyze targets for potential gene/environment interactions by 2015.	**3.9** $17,297,788 29 projects	**3.L.D** $9,135,505 12 projects	**3.L.D** $11,464,011 10 projects	**3.L.D** $11,567,250 10 projects	**3.L.D** $13,549,160 12 projects	**3.L.D** $17,799,693 15 projects	**$80,813,407**
	IACC Recommended Budget: $44,400,000 over 5 years						
Not specific to any objective	**3. Core/ Other Activities** $6,791,008 52 projects	**3. Core/ Other Activities** $8,512,980 39 projects	**3. Core/ Other Activities** $1,312,450 7 projects	**3. Core/ Other Activities** $724,770 5 projects	**3. Core/ Other Activities** $315,607 3 projects	**3. Core/ Other Activities** $537,826 3 projects	**$18,194,641**
Total funding for Question 3	**$82,846,620** 221 projects	**$100,043,216** 192 projects	**$81,231,647** 162 projects	**$60,209,628** 148 projects	**$56,487,026** 162 projects	**$55,666,352** 145 projects	**$436,484,489**

Question 3: Multiyear Funding Table, see Appendix C for a color-coding key and further details.

Table 6. Multiyear funding table for Question 3.

QUESTION 4

TREATMENTS AND INTERVENTIONS

***ASPIRATIONAL GOAL:* INTERVENTIONS WILL BE DEVELOPED THAT ARE EFFECTIVE FOR REDUCING BOTH CORE AND ASSOCIATED SYMPTOMS, FOR BUILDING ADAPTIVE SKILLS, AND FOR MAXIMIZING QUALITY OF LIFE AND HEALTH FOR PEOPLE WITH ASD.**

RESEARCH FOCUS OF QUESTION 4

Question 4 asks "Which treatments and interventions will help?" and covers a range of intervention approaches currently being considered, including pharmacological, behavioral, educational, occupational, technology-based, and alternative/complementary/integrative medicine approaches. Research in this field encompasses the development of new treatments using model systems and small-scale experiments as well as full-scale clinical trials. Question 4 also includes studies to assess the safety and effectiveness of treatments already in use in the community.

A word cloud was created to describe the research funded in Question 4 using the project titles listed under the question research area (**Figure 31**). 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 funded in Question 4.

Figure 31. Word cloud representing themes in Question 4 project titles.

ANALYSIS OF 2013 QUESTION 4 PORTFOLIO

Research focused on interventions and treatments (Question 4) received $58.1 million (19%) of total ASD funding in 2013. The number of projects assigned to Question 4 totaled 262 projects, which was 20% 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 Simons Foundation. Progress was made on all 12 of the Question 4 objectives in 2013. **Figure 32** provides a detailed overview of each objective's total funding in 2013 as well as the number of projects assigned to each objective.

As in previous years, the Question 4 objective receiving the most funding focuses on the development of model systems targeting areas for new interventions (4.S.B; $14.3 million, 25%). The second largest funded objective was 4.L.D which supports community-based studies assessing the effectiveness of interventions and services ($11.7 million; 20%). Objective 4.S.D followed with $10.4 million (18%) and supports investments in randomized controlled trials for early intervention. All other objectives received less funding in 2013, and 10% of Question 4 funding went to projects categorized as Core/Other. **Table 7** lists all the objectives and their progress to date.

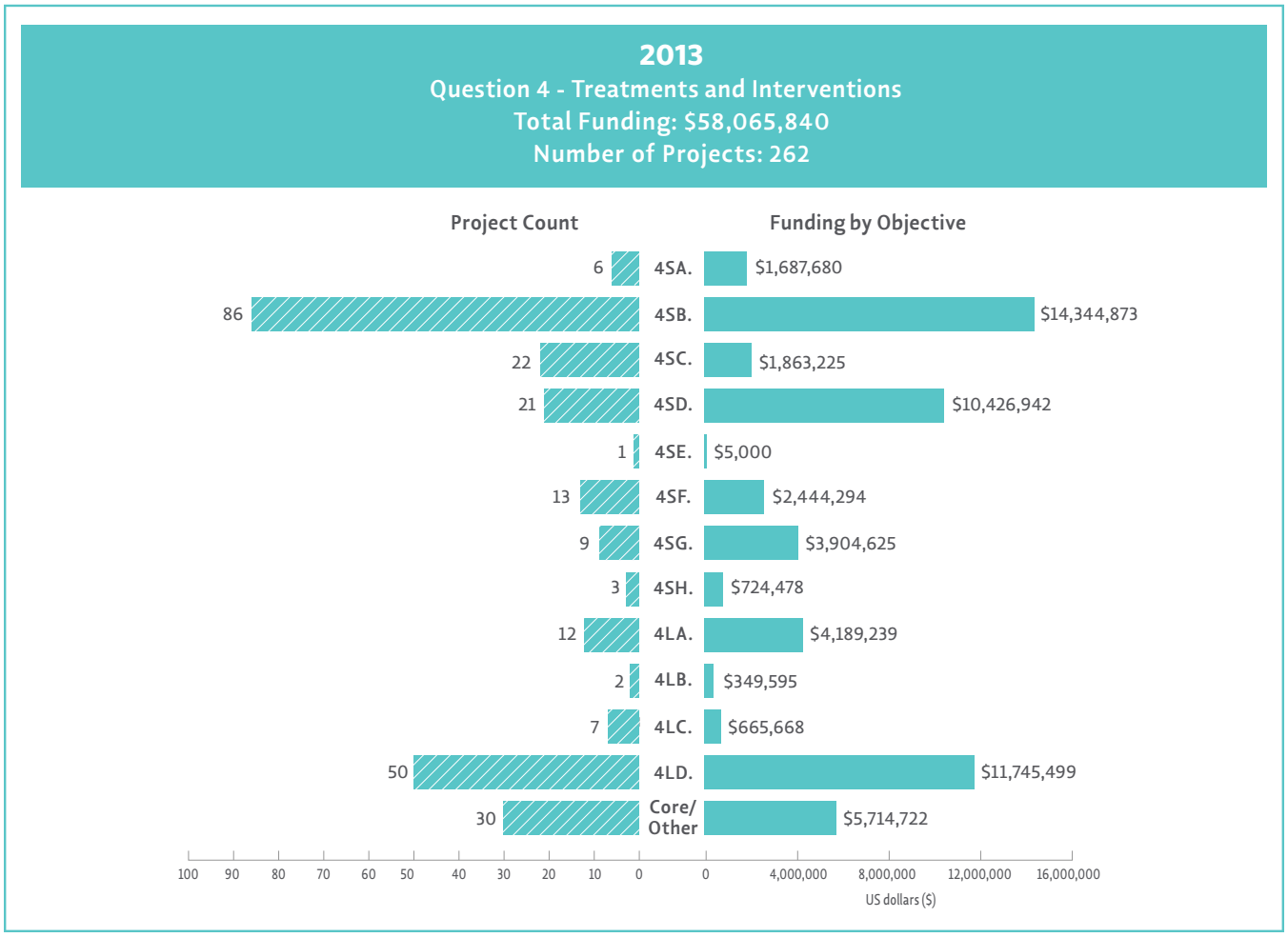


Figure 32. Question 4 objectives broken down by their funding and project count.

QUESTION 4 SUBCATEGORY ANALYSIS

Question 4 represents research on a wide array of different approaches to 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 accounted for approximately $58.1 million of total funding in 2013 and 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 33**).

The subcategories for Question 4 (Treatments and Interventions) illustrate the many approaches to treatments and interventions supported by autism research funders. In 2013, the largest amount of funding supported projects to develop **Behavioral** interventions (35%), including applied behavior analysis (ABA), cognitive therapy, and social skills training. Research on **Model systems/Therapeutic targets** (25%) followed, focusing on early development of animal and cellular models that mimic characteristics of ASD to test experimental therapies. **Educational** (classroom-based) interventions received 14% of funding, **Medical/Pharmacologic** interventions received 13% of funding, and **Technology-**

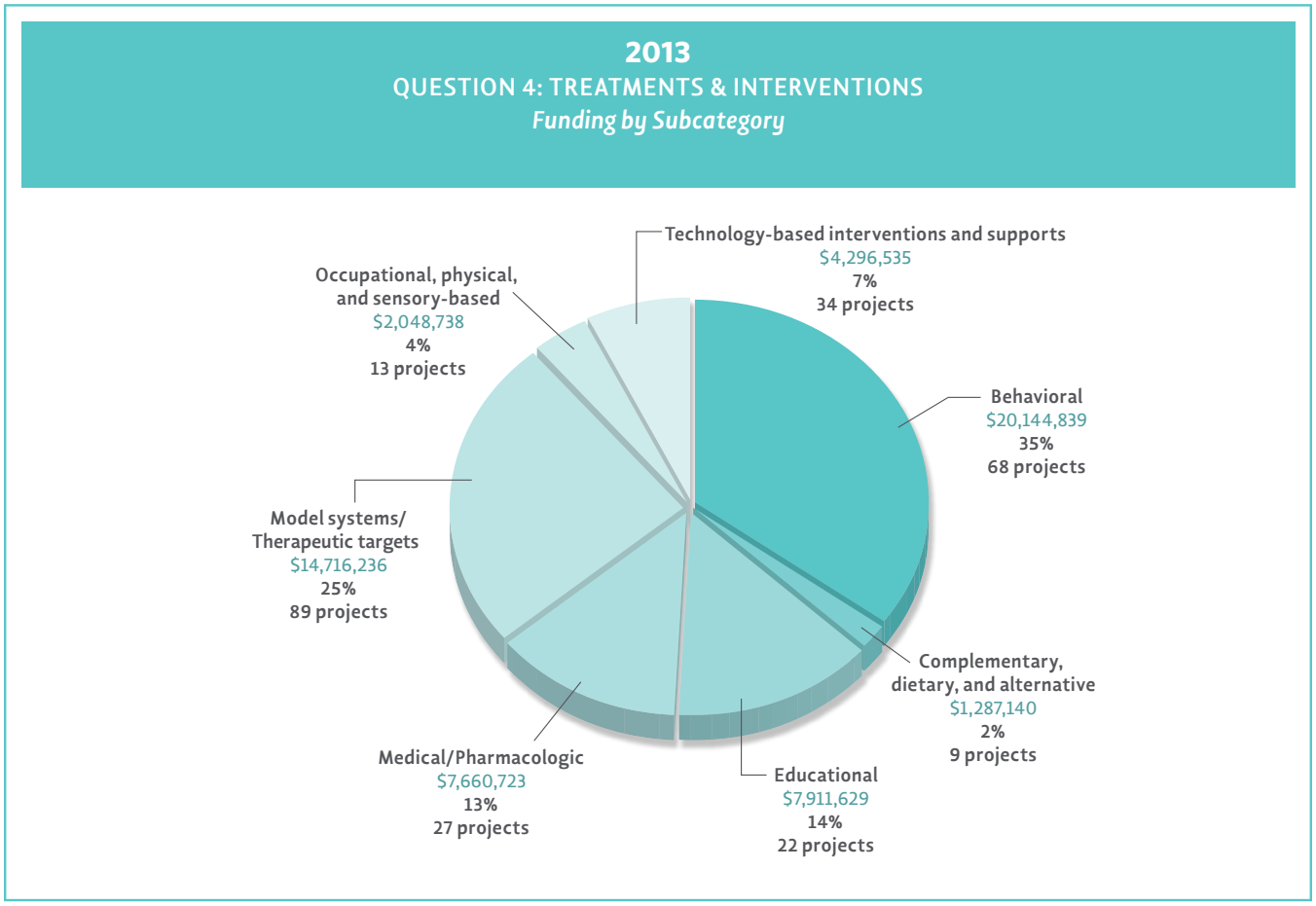


Figure 33. Question 4 funding by subcategory in 2013.

based interventions and supports received 7% of funding. The subcategories with the smallest amounts of funding included **Occupational, physical, and sensory-based** (4%) and **Complementary, dietary, and alternative** (2%) interventions.

PROGRESS MADE ON QUESTION 4 FROM 2008-2013

The trend in annual Question 4 funding over time is shown in **Figure 34**. Overall, research funding focused on treatments and interventions maintained a consistently high level over the six-year time span. In the most recent years, Question 4 has had one of the largest proportions of funding compared to other Question areas.

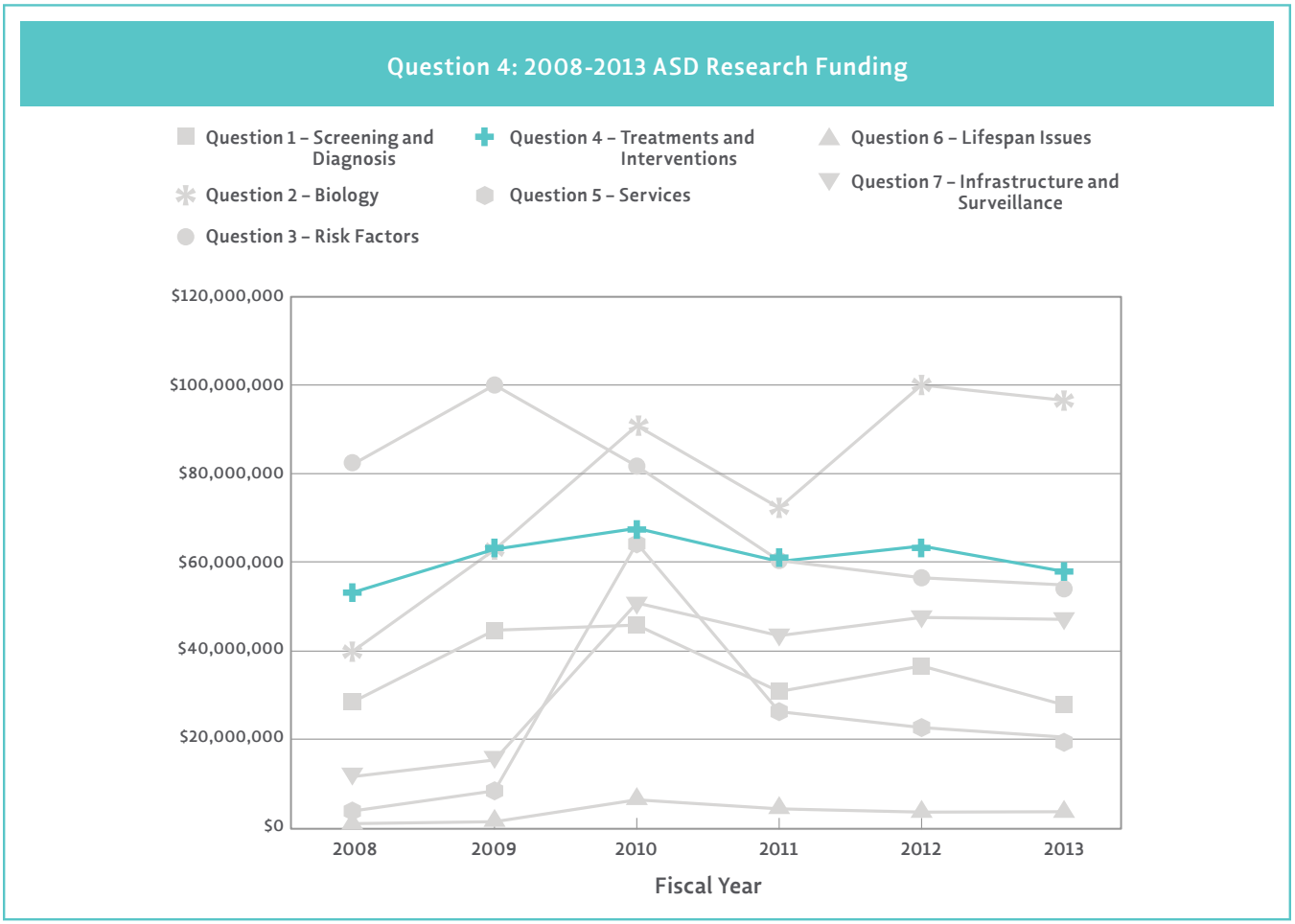


Figure 34. Question 4 ASD research funding from 2008-2013. Funding for Question 4 remained primarily flat, but relatively robust, over the six-year span.

PROGRESS MADE ON QUESTION 4 OBJECTIVES FROM 2008-2013

Based on the cumulative funding over six years, four objectives were considered completed, while the remaining eight objectives showed partial progress as of 2013 (**Figure 35**). Although all of the Question 4 objectives experienced some degree of growth in 2013, this is the same overall status across objectives that was reported for this Question in 2012. **Table 7** provides a snapshot of progress made on all 12 of the research objectives within Question 4 over the period from 2008-2013.

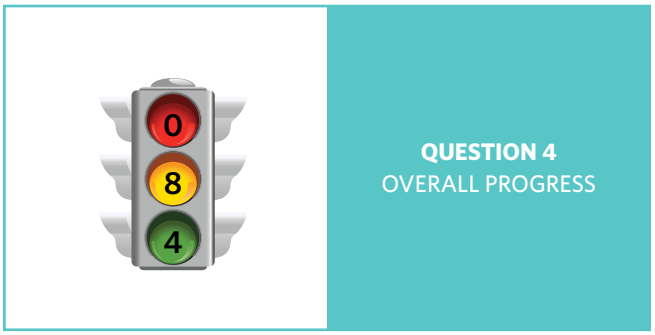


Figure 35. Overall status of progress for the 12 Question 4 objectives.

Question 4: Which Treatments And Interventions Will Help?

IACC Strategic Plan Objectives	Funding						
Year	**2008**	**2009**	**2010**	**2011**	**2012**	**2013**	**Total**
Support at least three randomized controlled trials that address co-occurring medical conditions associated with ASD by 2010.	**4.2** $4,583,171 5 projects	**4.S.A** $4,733,841 6 projects	**4.S.A** $3,787,700 4 projects	**4.S.A** $1,826,542 4 projects	**4.S.A** $2,174,124 3 projects	**4.S.A** $1,687,680 6 projects	**$18,793,058**
	IACC Recommended Budget: $13,400,000 over 3 years						
Standardize and validate at least 20 model systems (e.g., cellular and/or animal) that replicate features of ASD and will allow identification of specific molecular targets or neural circuits amenable to existing or new interventions by 2012.	**4.5** $15,879,827 42 projects	**4.S.B** $20,162,709 70 projects	**4.S.B** $23,229,501 92 projects	**4.S.B** $21,606,118 89 projects	**4.S.B** $21,232,514 94 projects	**4.S.B** $14,344,873 86 projects	**$116,455,542**
	IACC Recommended Budget: $75,000,000 over 5 years						
Test safety and efficacy of at least five widely used interventions (e.g., nutrition, medications, assisted technologies, sensory integration, medical procedures) that have not been rigorously studied for use in ASD by 2012.	**4.6** $641,285 8 projects	**4.S.C** $3,252,941 29 projects	**4.S.C** $1,509,745 18 projects	**4.S.C** $2,254,724 18 projects	**4.S.C** $1,288,226 17 projects	**4.S.C** $1,863,225 22 projects	**$10,810,146**
	IACC Recommended Budget: $27,800,000 over 5 years						
Complete two multi-site randomized controlled trials of comprehensive early intervention that address core symptoms, family functioning and community involvement by 2013.	**4.7** $4,236,869 5 projects	**4.S.D** $7,540,613 9 projects	**4.S.D** $10,306,148 18 projects	**4.S.D** $11,156,647 20 projects	**4.S.D** $8,848,130 21 projects	**4.S.D** $10,426,942 21 projects	**$52,515,349**
	IACC Recommended Budget: $16,700,000 over 5 years						
Convene a workshop to advance the understanding of clinical subtypes and treatment personalization (i.e., what are the core symptoms to target for treatment studies) by 2011.	N/A	**4.S.E** $0 0 projects	**4.S.E** $0 0 projects	**4.S.E*** $26,000 1 project	**4.S.E*** $0 0 projects	**4.S.E*** $5,000 1 project	**$31,000**
	IACC Recommended Budget: $50,000 **This objective was partially completed in 2011*						
Launch randomized controlled trials of interventions including biological signatures and other measures to predict response, and monitor quality of life and functional outcomes in each of the following groups: • Five trials in infants and toddlers by 2013. ***IACC Recommended Budget: $30,000,000 over 5 years (revised in 2010)*** • Three trials in school-aged children and/or adolescents by 2013. ***IACC Recommended Budget: $18,000,000 over 5 years (revised in 2010)*** • Three trials in adults by 2014. ***IACC Recommended Budget: $18,000,000 over 5 years***	**4.3 & 4.4** $12,109,516 16 projects & 30 projects	**4.S.F** $9,791,270 42 projects	**4.S.F** $7,575,212 30 projects	**4.S.F** $5,445,599 23 projects	**4.S.F** $6,255,438 21 projects	**4.S.F** $2,444,294 13 projects	**$43,621,329**
	Total IACC Recommended Budget: $66,000,000 over 5 years						

Question 4: Multiyear Funding Table, see Appendix C for a color-coding key and further details.

Question 4: Which Treatments And Interventions Will Help?

IACC Strategic Plan Objectives	Funding						
Year	2008	2009	2010	2011	2012	2013	Total
Support at least five studies on interventions for nonverbal individuals with ASD by 2012. Such studies may include: • Projects examining service-provision models that enhance access to augmentative and alternative communication (AAC) supports in both classroom and adult service-provision settings, such as residential service-provision and the impact of such access on quality of life, communication, and behavior; • Studies of novel treatment approaches that facilitate communication skills in individuals who are nonverbal, including the components of effective AAC approaches for specific subpopulations of people with ASD; and • Studies assessing access and use of AAC for children and adults with ASD who have limited or partially limited speech and the impact on functional outcomes and quality of life.	N/A	N/A	**4.S.G** $1,907,721 11 projects	**4.S.G** $2,830,851 13 projects	**4.S.G** $4,991,831 17 projects	**4.S.G** $3,904,625 9 projects	**$13,635,028**
			IACC Recommended Budget: $3,000,000 over 2 years				
Support at least two studies that focus on research on health promotion and prevention of secondary conditions in people with ASD by 2012. Secondary conditions of interest include weight issues and obesity, injury, and co-occurring psychiatric and medical conditions.	N/A	N/A	**4.S.H** $225,877 2 projects	**4.S.H** $222,265 1 project	**4.S.H** $956,827 4 projects	**4.S.H** $724,478 3 projects	**$2,129,447**
			IACC Recommended Budget: $5,000,000 over 3 years				
Complete at least three randomized controlled trials on medications targeting core symptoms in people with ASD of all ages by 2014.	**4.8** $1,380,376 12 projects	**4.L.A** $1,168,146 10 projects	**4.L.A** $1,924,932 11 projects	**4.L.A** $1,527,858 12 projects	**4.L.A** $3,713,783 14 projects	**4.L.A** $4,189,239 12 projects	**$13,904,334**
			IACC Recommended Budget: $22,200,000 over 5 years				
Develop interventions for siblings of people with ASD with the goal of reducing the risk of recurrence by at least 30% by 2014.	**4.9** $14,256 1 project	**4.L.B** $132,263 2 projects	**4.L.B** $307,349 3 projects	**4.L.B** $14,256 2 projects	**4.L.B** $362,987 2 projects	**4.L.B** $349,595 2 projects	**$1,180,706**
			IACC Recommended Budget: $6,700,000 over 5 years				
Conduct at least one study to evaluate the safety and effectiveness of medications commonly used in the treatment of co-occurring conditions or specific behavioral issues in people with ASD by 2015.	N/A	**4.L.C** $1,061,222 7 projects	**4.L.C** $2,302,240 7 projects	**4.L.C** $2,834,887 8 projects	**4.L.C** $277,072 3 projects	**4.L.C** $665,668 7 projects	**$7,141,089**
			IACC Recommended Budget: $10,000,000 over 5 years				

Question 4: Multiyear Funding Table, see Appendix C for a color-coding key and further details.

Question 4: Which Treatments And Interventions Will Help?

IACC Strategic Plan Objectives	Funding						
Year	2008	2009	2010	2011	2012	2013	Total
Support at least five community-based studies that assess the effectiveness of interventions and services in broader community settings by 2015. Such studies may include comparative effectiveness research studies that assess the relative effectiveness of: • Different and/or combined medical, pharmacological, nutritional, behavioral, service-provision, and parent- or caregiver-implemented treatments; • Scalable early intervention programs for implementation in underserved, low-resource, and low-literacy populations; and • Studies of widely used community intervention models for which extensive published data are not available. Outcome measures should include assessment of potential harm as a result of autism treatments, as well as positive outcomes.	N/A	N/A	**4.L.D** $8,756,832 32 projects	**4.L.D** $6,296,024 32 projects	**4.L.D** $10,186,313 45 projects	**4.L.D** $11,745,499 50 projects	**$36,984,668** *IACC Recommended Budget: $37,500,000 over 3 years*
Not specific to any objective	**4. Core/ Other Activities** $14,075,905 54 projects	**4. Core/ Other Activities** $15,560,011 59 projects	**4. Core/ Other Activities** $6,290,634 49 projects	**4. Core/ Other Activities** $4,777,350 37 projects	**4. Core/ Other Activities** $3,862,655 29 projects	**4. Core/ Other Activities** $5,714,722 30 projects	**$50,281,277**
Total funding for Question 4†	**$53,968,973** 178 projects	**$63,403,016** 234 projects	**$68,123,891** 277 projects	**$60,819,121** 260 projects	**$64,149,900** 270 projects	**$58,065,840** 262 projects	**$368,530,738***

Question 4: Multiyear Funding Table, see Appendix C for a color-coding key and further details.

*This total reflects all funding for projects aligned to current objectives in the *2011 IACC Strategic Plan* and incorporates funding for projects that may have been coded differently in previous versions of the *Plan*.

†The totals reflect the funding and projects coded to this Question of the *Strategic Plan* in the particular year indicated at the top of the column. When reading each column vertically, please note that the projects and funding associated with each objective for 2008 may not add up to the total at the bottom of the column; this is due to revisions of the *Strategic Plan* that caused some objectives to be shifted to other Questions under the *Plan*. The projects and funding associated with these reclassified objectives are now reflected under the Question in which they appear in the *2011 Strategic Plan*.

Table 7. Multiyear funding table for Question 4.

QUESTION 5

SERVICES

***ASPIRATIONAL GOAL:* COMMUNITIES WILL ACCESS AND IMPLEMENT NECESSARY HIGH-QUALITY, EVIDENCE-BASED SERVICES AND SUPPORTS THAT MAXIMIZE QUALITY OF LIFE AND HEALTH ACROSS THE LIFESPAN FOR ALL PEOPLE WITH ASD.**

RESEARCH FOCUS OF QUESTION 5

Question 5 ("Where can I turn for services?") focuses on services and supports for people with ASD. Objectives address issues including access to services for both individuals with ASD and their families, impact of self-directed care, coordination among State and local agencies' community-based supports, and the assessment of the health, safety, and mortality of people with ASD. Question 5 also includes research to develop and evaluate the training of service providers (pediatricians, teachers, social workers, etc.), and improve the efficacy, cost-effectiveness, and dissemination of evidence-based practices.

In an effort to provide a visual representation of the research funded in Question 5 in 2013, a word cloud was generated using the project titles listed under this question (**Figure 36**). 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 funded in Question 5.

Figure 36. Word cloud representing themes in Question 5 project titles.

ANALYSIS OF 2013 QUESTION 5 PORTFOLIO

Projects assigned to Question 5 comprised 7% ($20.0 million) of the total ASD research supported in 2013. Question 5 consisted of 125 projects, which was 10% of the total number of projects. The largest funders of Question 5 are the Department of Education, the National Institutes of Health, and the Centers for Disease Control and Prevention. Of the nine Question 5 objectives, three objectives achieved their recommended annual funding target, four partially saw activity, and two objectives (5.S.B and 5.L.D) had no active projects or funding in this year. **Figure 37** provides a detailed overview of each objective's total funding in 2013 as well as the number of projects assigned to each objective.

The majority of projects that were categorized under this question did not fit into any of the specific Question 5 objectives and were assigned as Core/Other ($7.3 million, 36%). The next largest portion of funding went to 5.L.A, which supports projects improving dissemination, implementation, and sustainability of evidenced-based interventions ($6.7 million, 33%). Objective 5.L.C, research focused on the evaluation of new and existing training of service providers, followed with $3.4 million and 17% of Question 5 funding in 2013. Objectives 5.S.B and 5.L.D were not funded in 2013, but have received funding in previous years. **Table 8** lists all the objectives and their progress to date.

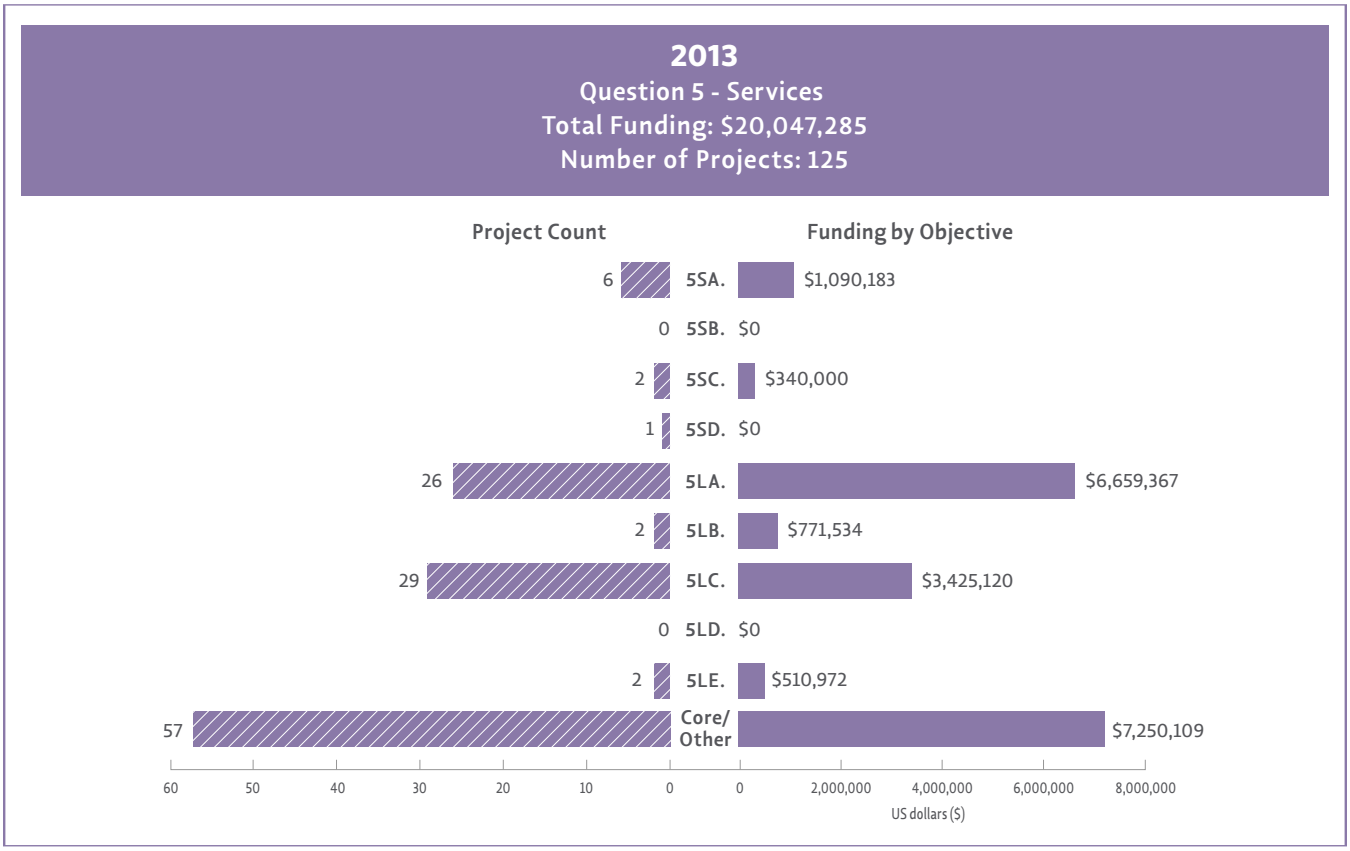


Figure 37. Question 5 objectives broken down by their funding and project count.

QUESTION 5 SUBCATEGORY ANALYSIS

Projects within Question 5, which accounted for approximately $20.0 million in 2013, 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 38**).

In 2013, research falling under the development and evaluation of **Practitioner training** subcategory accounted for almost two thirds (64%) of the funding for Question 5. 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 18% of the Question 5 funding. Research focused on disparities and potential barriers to access are covered in **Services utilization and access** and accounted for 10%. **Family well-being and safety** research projects received 6% of funding, and projects relating to **Community inclusion programs** received 2% of Question 5 funding in 2013.

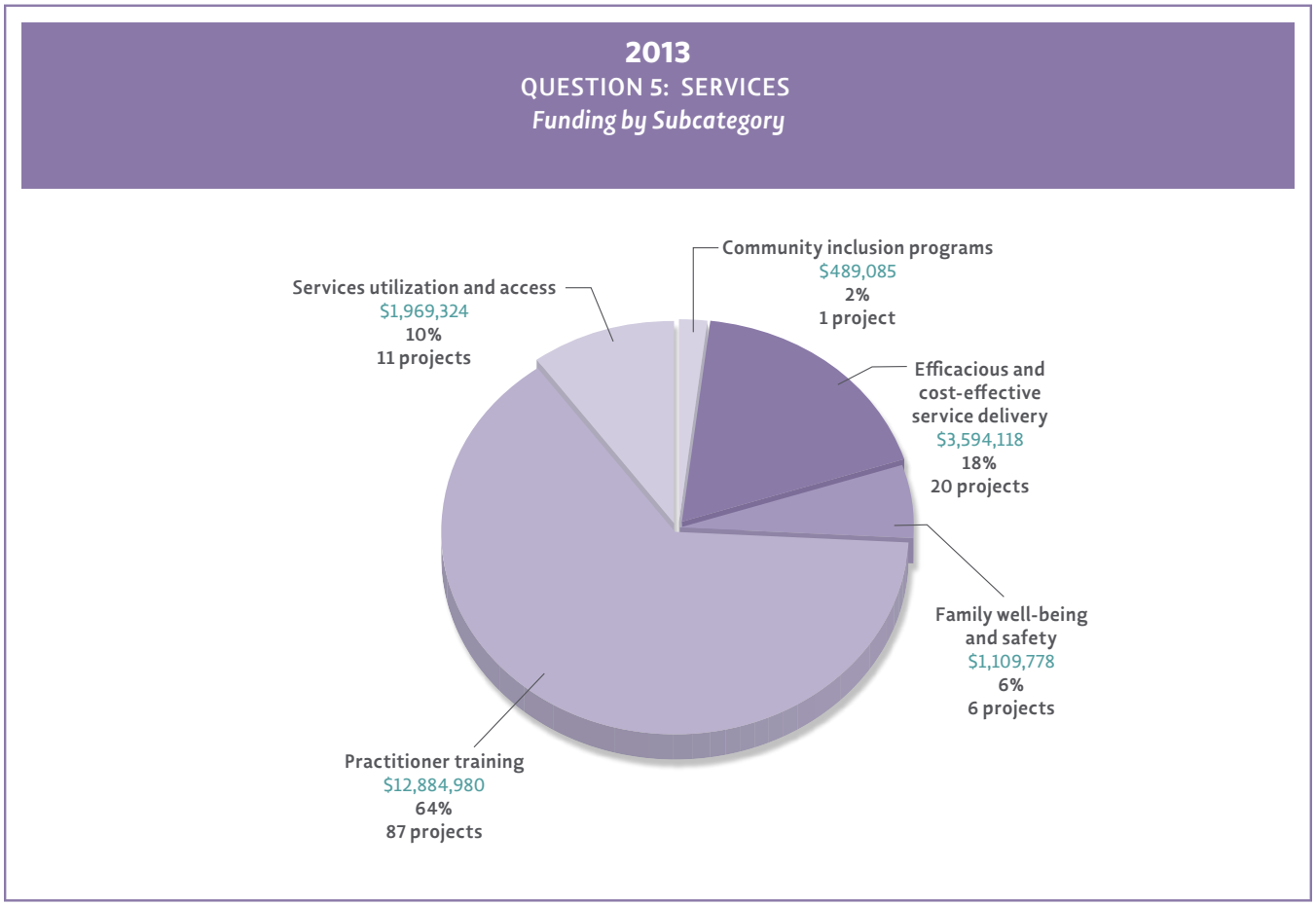


Figure 38. Question 5 funding by subcategory in 2013.

PROGRESS MADE ON QUESTION 5 FROM 2008-2013

Figure 39 shows the trend in Question 5 funding over time using the adjusted funding total from **Table 8**. The adjusted funding (solid line) reflects funding for projects aligned to objectives in the *2011 IACC Strategic Plan* that may have been coded differently under previous versions of the plan. 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.

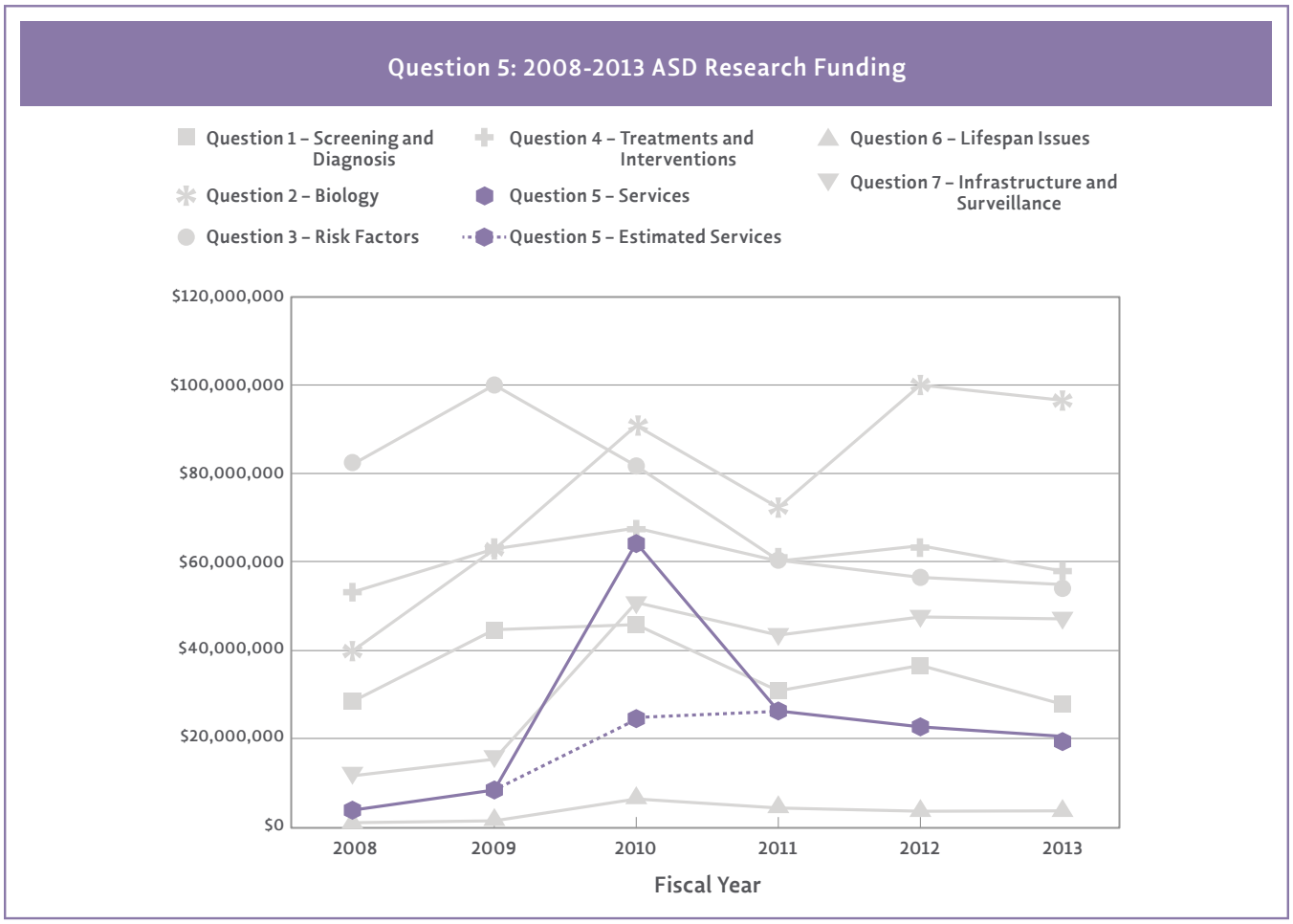


Figure 39. Question 5 ASD research funding from 2008-2013. Funding for Question 5 remained relatively low over the six-year span and decreased slightly after 2010.

As mentioned in the *2011-2012 Portfolio Analysis Report*, adjustments in reporting were made to only report autism-specific and research-related portions of larger projects. An estimated line for Question 5 funding in 2010 (dashed line) is included in the graph to enable a more accurate comparison among years. To calculate the estimated line for 2010, the same methodology for the prorated rates used in 2011 to 2013 was applied. (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). When these adjustments are made to the 2010 data set, the change from 2009 to 2010, and 2010 to 2011, appear to be less significant. Overall, when comparing 2008 funding for Question 5 with 2013 funding the general trend is upward, though Question 5 also gained several new objectives from the latest version of the *Strategic Plan*, which also contributed to the rise.

PROGRESS MADE ON QUESTION 5 OBJECTIVES FROM 2008-2013

An assessment of progress made on Question 5 objectives over the six-year funding period shows that three objectives were considered completed as of 2013. The other six objectives achieved partial progress toward their overall recommended budgeted goals since 2008 (**Figure 40**), despite the fact that two of these objectives did not see activity in 2013 specifically. Although many of the Question 5 objectives experienced growth in 2013, the overall status of Question 5 objectives did not change since 2012. **Table 8** provides a snapshot of progress made on all nine of the research objectives within Question 5 over the period from 2008-2013.

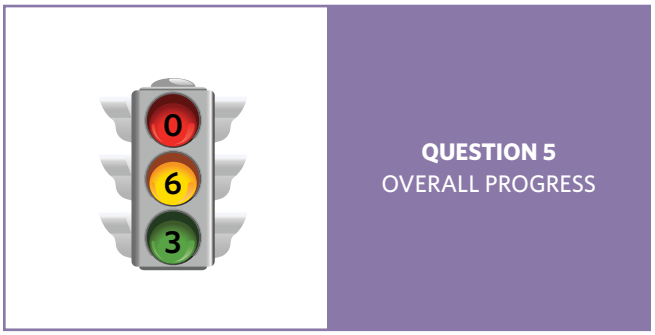


Figure 40. Overall status of progress for the nine Question 5 objectives.

Question 5: Where Can I Turn For Services?

IACC Strategic Plan Objectives	Funding						
Year	2008	2009	2010	2011	2012	2013	Total
Support two studies that assess how variations in and access to services affect family functioning in diverse populations, including underserved populations, by 2012.	5.2 $0 0 projects	5.S.A $499,999 1 project	5.S.A $2,061,834 9 projects	5.S.A $1,351,793 8 projects	5.S.A $1,364,087 6 projects	5.S.A $1,090,183 6 projects	$6,367,896
	IACC Recommended Budget: $1,000,000 over 3 years						
Conduct one study to examine how self-directed community-based services and supports impact children, youth, and adults with ASD across the spectrum by 2014.	N/A	5.S.B $446,340 6 projects	5.S.B $291,635 6 projects	5.S.B $0 1 project	5.S.B $0 0 projects	5.S.B $0 0 projects	$737,975
	IACC Recommended Budget: $6,000,000 over 3 years						
Implement and evaluate five models of policy and practice-level coordination among State and local agencies to provide integrated and comprehensive community-based supports and services that enhance access to services and supports, self-determination, economic self-sufficiency, and quality of life for people with ASD across the spectrum and their families, (which may include access to augmentative and alternative communication [AAC] technology), with at least one project aimed at the needs of transitioning youth and at least one study to evaluate a model of policy and practice-level coordination among State and local mental health agencies serving people with ASD, by 2015.	N/A	5.S.C $0 0 projects	5.S.C $4,225,315 15 projects	5.S.C $600,000 3 projects	5.S.C $600,000 2 projects	5.S.C $340,000 2 projects	$5,765,315
	IACC Recommended Budget: $25,000,000 over 5 years						
Support two studies to examine health, safety, and mortality issues for people with ASD by 2012.	N/A	N/A	5.S.D $159,135 3 projects	5.S.D $0 1 project	5.S.D $5,000 1 project	5.S.D $0 1 project	$164,135
	IACC Recommended Budget: $4,500,000 over 3 years						
Test four methods to improve dissemination, implementation, and sustainability of evidence-based interventions, services, and supports in diverse community settings by 2013.	5.4 $2,596,838 3 projects	5.L.A $5,460,809 10 projects	5.L.A $7,747,912 22 projects	5.L.A $5,840,814 24 projects	5.L.A $7,210,677 32 projects	5.L.A $6,659,367 26 projects	$35,516,417
	IACC Recommended Budget: $7,000,000						
Test the efficacy and cost-effectiveness of at least four evidence-based services and supports for people with ASD across the spectrum and of all ages living in community settings by 2015.	5.3 $0 0 projects	5.L.B $103,722 5 projects	5.L.B $0 0 projects	5.L.B $0 0 projects	5.L.B $499,995 1 project	5.L.B $771,534 2 projects	$1,375,251
	IACC Recommended Budget: $16,700,000 over 5 years						
Evaluate new and existing pre-service and in-service training to increase skill levels in service providers, including direct support workers, parents and legal guardians, education staff, and public service workers, to benefit the spectrum of people with ASD and to promote interdisciplinary practice by 2015.	6.3 $30,000 1 project	5.L.C $132,494 6 projects	5.L.C $36,433,257 83 projects	5.L.C $6,048,734 30 projects	5.L.C $3,724,262 29 projects	5.L.C $3,425,120 29 projects	$49,793,867
	IACC Recommended Budget: $8,000,000						

Question 5: Multiyear Funding Table, see Appendix C for a color-coding key and further details.

Question 5: Where Can I Turn For Services?

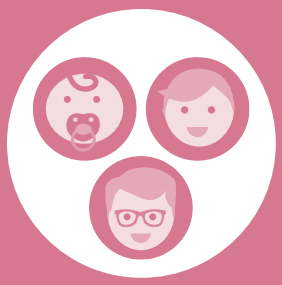
IACC Strategic Plan Objectives	Funding						
Year	2008	2009	2010	2011	2012	2013	Total
Evaluate at least two strategies or programs to increase the health and safety of people with ASD that simultaneously consider principles of self-determination and personal autonomy by 2015.	N/A	N/A	**5.L.D** $296,840 5 projects	**5.L.D** $279,999 4 projects	**5.L.D** $54,999 3 projects	**5.L.D** $0 0 projects	**$631,838**
			IACC Recommended Budget: $2,700,000 over 3 years				
Support three studies of dental health issues for people with ASD by 2015. This should include: • One study on the cost-benefit of providing comprehensive dental services, including routine, non-emergency medical and surgical dental services, denture coverage, and sedation dentistry to adults with ASD as compared to emergency and/or no treatment. • One study focusing on the provision of accessible, person-centered, equitable, effective, safe, and efficient dental services to people with ASD. • One study evaluating pre-service and in-service training program to increase skill levels in oral health professionals to benefit people with ASD and promote interdisciplinary practice.	N/A	N/A	**5.L.E** $196,457 2 projects	**5.L.E** $443,860 3 projects	**5.L.E** $307,784 2 projects	**5.L.E** $510,972 2 projects	**$1,459,073**
			IACC Recommended Budget: $2,700,000 over 3 years				
Not specific to any objective	**5. Core/ Other Activities** $1,247,714 5 projects	**5. Core/ Other Activities** $2,004,687 8 projects	**5. Core/ Other Activities** $13,436,737 66 projects	**5. Core/ Other Activities** $11,553,704 63 projects	**5. Core/ Other Activities** $9,060,297 62 projects	**5. Core/ Other Activities** $7,250,109 57 projects	**$44,553,248**
Reported funding for Question 5*	**$1,685,222** 13 projects	**$8,648,050** 36 projects	**$64,849,122** 211 projects	**$26,118,904** 137 projects	**$22,827,101** 138 projects	**$20,047,285** 125 projects	**$144,175,684**
Adjusted funding for Question 5†	**$3,874,552** 9 projects	**$8,648,051** 36 projects	**$64,849,122** 211 projects	**$26,118,904** 137 projects	**$22,827,101** 138 projects	**$20,047,285** 125 projects	**$146,365,015**

Question 5: Multiyear Funding Table, see Appendix C for a color-coding key and further details.

*The "Reported funding" totals reflect the funding and projects originally coded to this Question of the *Strategic Plan*, as reported in the *Portfolio Analysis* Report corresponding to the year indicated at the top of the column. When reading each column of the table vertically, please note that the projects and funding associated with each objective for the years 2008 and 2009 may not add up to the reported funding total at the bottom of the column; this is due to adjustments made to account for revisions in the *Strategic Plan*, which caused the shifting of some objectives to other Questions under the *Plan*. The projects and funding associated with these reclassified objectives are now reflected under the Question in which they appear in the *2011 Strategic Plan*.

†The "Adjusted funding" total reflects funding for projects aligned to objectives in the *2011 IACC Strategic Plan* (the most recent version in which objectives were revised) and incorporates funding for projects that may have been coded differently under previous versions of the *Plan*.

Table 8. Multiyear Funding Table for Question 5.



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, MEANINGFUL RELATIONSHIPS, AND ACCESS TO NECESSARY AND INDIVIDUALIZED 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 "What does the future hold, particularly for adults?" Question 6 encompasses research to identify and address issues surrounding transition to adulthood, access to services across the lifespan, and quality of life. Some of the research in Question 6 represents projects that assess the long-term outcomes (in terms of 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 education system to 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 2013, a word cloud was created using the project titles listed under this question (**Figure 41**). 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 funded in Question 6.

Figure 41. Word cloud representing themes in Question 6 project titles.

ANALYSIS OF 2013 QUESTION 6 PORTFOLIO

In 2013, research on lifespan issues associated with ASD (Question 6) accounted for 1% ($3.2 million) of total ASD research funding and included 27 projects (2% of all projects). This Question area has the smallest number of projects (27) and the smallest number of funders involved —only seven organizations and agencies (**Figure 11**). The agencies and organizations with the largest stakes are the National Institutes of Health, Autism Speaks, and the Department of Education. Question 6 consists of eight objectives. In 2013, five objectives received funding, one objective included an active project with no funding, and two objectives did not have any active projects or funding. **Figure 42** provides a detailed overview of each objective's total funding in 2013 as well as the number of projects assigned to each objective.

Studies assessing quality of life for adults with ASD and service delivery systems (6.S.A) received the most funding in Question 6 ($1.1 million; 35%) and had the greatest number of projects (9 projects). The next largest portion of funding for this question went to projects that did not fit into any of the specific Question 6 research objectives and were assigned as Core/Other ($1.1 million, 35%). The remaining objectives in Question 6 that received funding received significantly smaller portions of funding. Objectives 6.S.B and 6.L.C did not receive funding but have been funded in previous years. **Table 9** lists all the objectives and their progress to date.

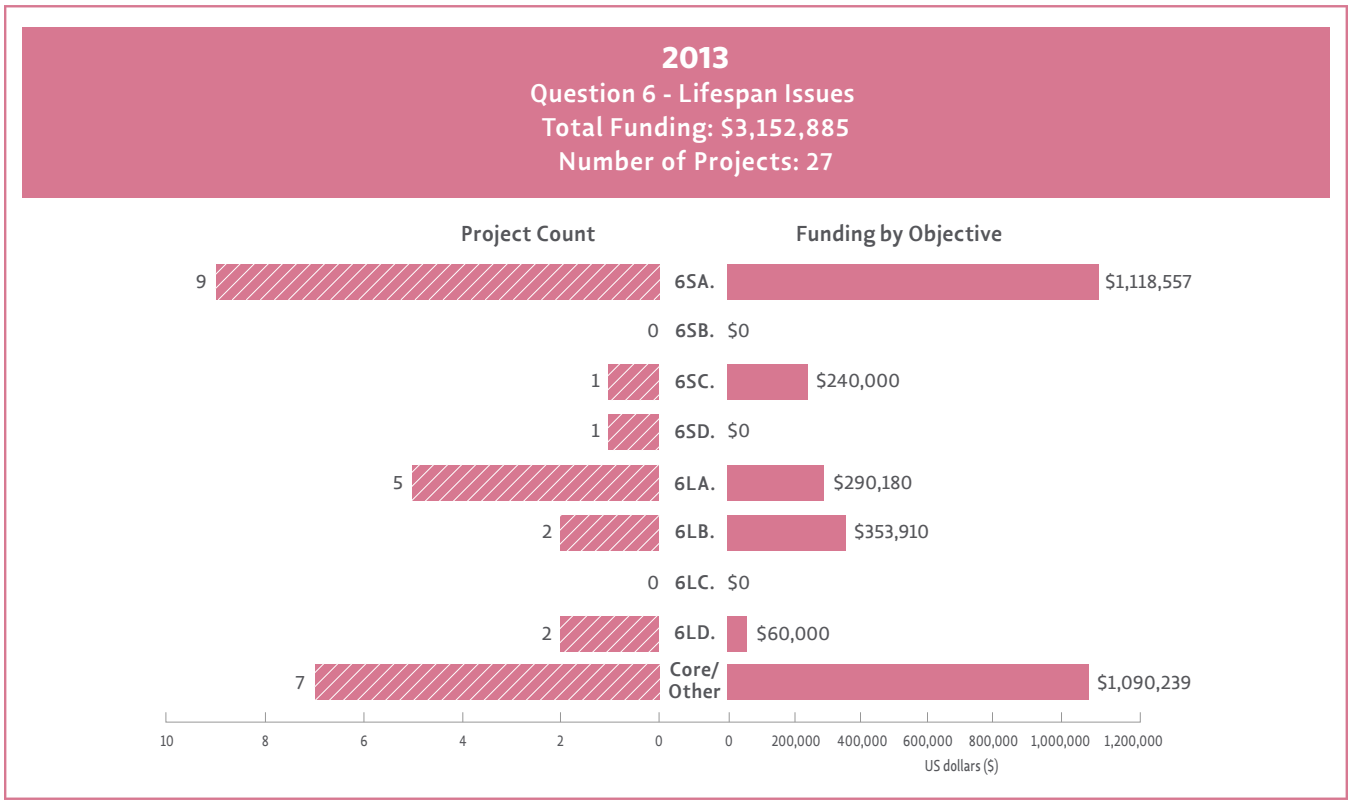


Figure 42. Question 6 objectives broken down by their funding and project count.

QUESTION 6 SUBCATEGORY ANALYSIS

Because Question 6 had so few assigned projects (27) and only $3.2 million of total ASD funding in 2013, and because many projects encompassed more than one topic, it was difficult to formulate and group the research into subcategories in the same fashion as was done for the other questions. However, this will likely change as the research field concerned with ASD across the lifespan grows and matures, allowing the development of subcategories in the future.

PROGRESS MADE ON QUESTION 6 FROM 2008-2013

Figure 43 shows the trend in Question 6 funding over time using the adjusted funding total in **Table 9**. The adjusted funding reflects funding for projects aligned to objectives in the *2011 IACC Strategic Plan* that may have been coded differently under previous versions of the plan. Research related to Question 6 received the lowest level of annual funding for the six-year time period. Although there was a small increase in funding for this question area from 2009-2010, the overall trend shows that funding for this question has stayed low and relatively flat over the six-year period.

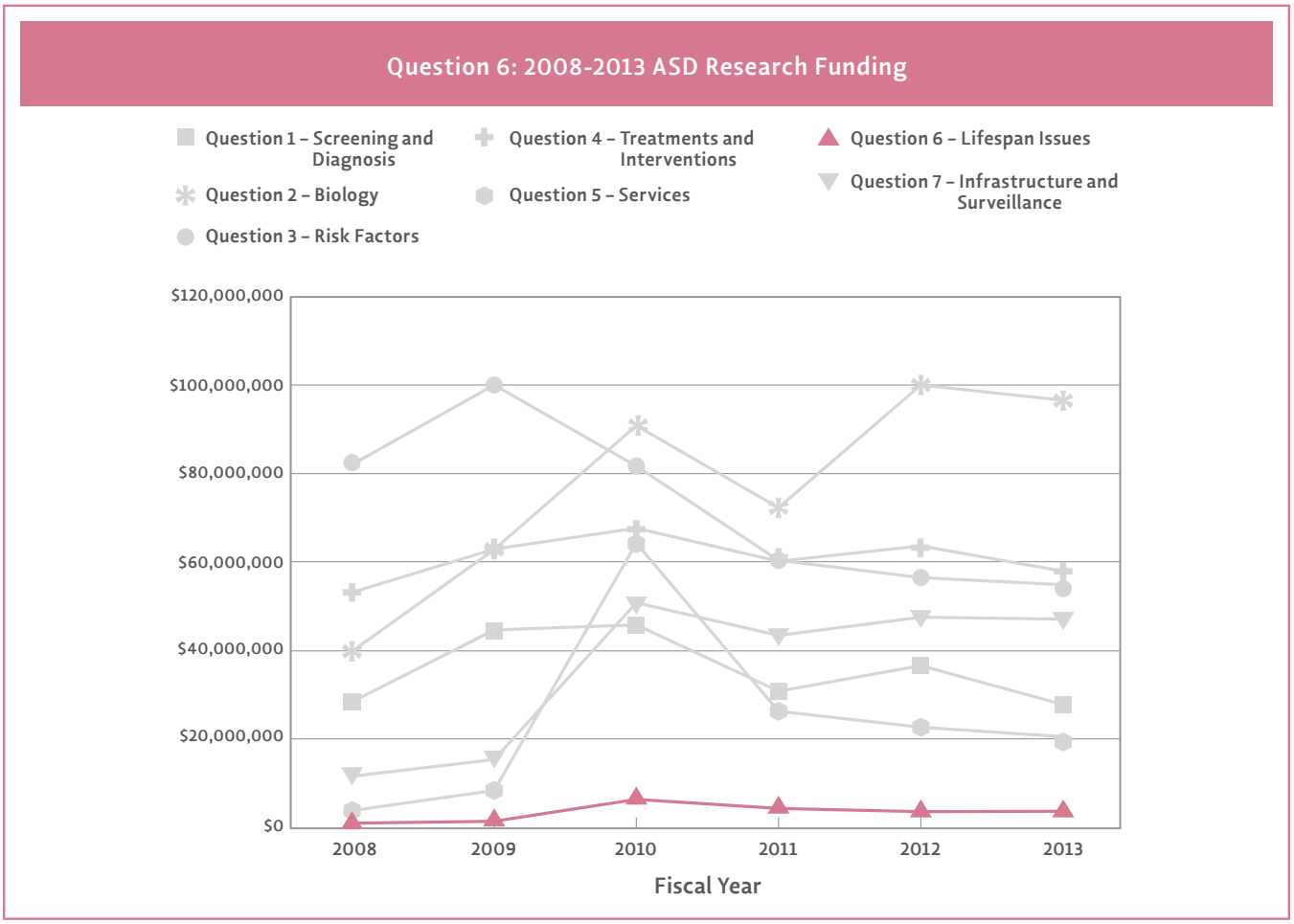


Figure 43. Question 6 ASD research funding from 2008-2013. Funding for Question 6 remained low over the six-year span and overall experienced a gradual decrease.

PROGRESS MADE ON QUESTION 6 OBJECTIVES FROM 2008-2013

All of the eight Question 6 objectives have been partially completed since 2008 (**Figure 44**). However, only some of the Question 6 objectives saw growth in 2013, and this 2013 progress was not enough to change the overall status of any of the objectives from what was reported in 2012. After six years of monitoring progress in this Question area, none of the objectives have achieved completed status. **Table 9** provides a snapshot of progress made on all eight of the research objectives within Question 6 over the period from 2008-2013.

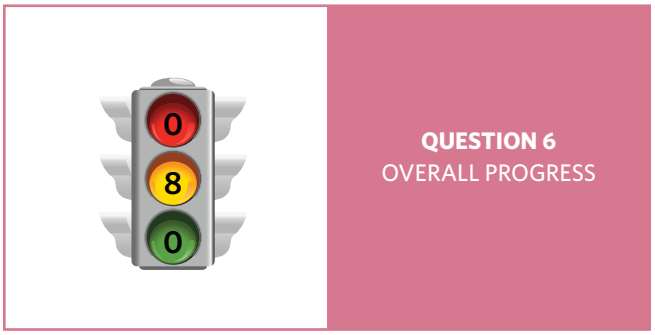


Figure 44. Overall status of progress for the eight Question 6 objectives.

Question 6: What Does The Future Hold, Particularly For Adults?

IACC Strategic Plan Objectives	Funding						
Year	2008	2009	2010	2011	2012	2013	Total
Launch at least two studies to assess and characterize variation in the quality of life for adults on the ASD spectrum as it relates to characteristics of the service delivery system (e.g., safety, integrated employment, post-secondary educational opportunities, community inclusion, self-determination, relationships, and access to health services and community-based services) and determine best practices by 2012.	6.2 $60,000 1 project	6.S.A $20,000 1 project	6.S.A $283,837 2 projects	6.S.A $542,193 6 projects	6.S.A $1,013,156 10 projects	6.S.A $1,118,557 9 projects	$3,037,743
	IACC Recommended Budget: $5,000,000 over 3 years						
Evaluate at least one model, at the State and local level, in which existing programs to assist people with disabilities (e.g., Social Security Administration, Rehabilitation Services Administration) meet the needs of transitioning youth and adults with ASD by 2013.	N/A	6.S.B $0 0 projects	6.S.B $700,000 2 projects	6.S.B $700,000 2 projects	6.S.B $700,000 2 projects	6.S.B $0 0 projects	$2,100,000
		IACC Recommended Budget: $5,000,000 over 3 years					
Develop one method to identify adults across the ASD spectrum who may not be diagnosed, or are misdiagnosed, to support service linkage, better understand prevalence, and track outcomes with consideration of ethical issues (insurance, employment, stigma) by 2015.	N/A	6.S.C $0 0 projects	6.S.C $28,000 1 project	6.S.C $28,000 1 project	6.S.C $0 1 project	6.S.C $240,000 1 project	$296,000
		IACC Recommended Budget: $8,400,000 over 5 years					
Conduct at least one study to measure and improve the quality of lifelong supports being delivered in community settings to adults across the spectrum with ASD through provision of specialized training for direct care staff, parents, and legal guardians, including assessment and development of ASD-specific training, if necessary, by 2015.	N/A	6.S.D $0 0 projects	6.S.D $619,163 3 projects	6.S.D $0 2 projects	6.S.D $0 1 project	6.S.D $0 1 project	$619,163
		IACC Recommended Budget: $7,500,000 over 5 years					
Develop at least two individualized community-based interventions that improve quality of life or health outcomes for the spectrum of adults with ASD by 2015.	6.5 $0 0 projects	6.L.A $509,965 2 projects	6.L.A $2,285,071 18 projects	6.L.A $2,154,170 15 projects	6.L.A $616,119 11 projects	6.L.A $290,180 5 projects	$5,855,505
		IACC Recommended Budget: $12,900,000 over 5 years					
Conduct one study that builds on carefully characterized cohorts of children and youth with ASD to determine how interventions, services, and supports delivered during childhood impact adult health and quality of life outcomes by 2015.	N/A	6.L.B $718,290 2 projects	6.L.B $1,280,790 3 projects	6.L.B $1,348,557 4 projects	6.L.B $639,346 2 projects	6.L.B $353,910 2 projects	$4,340,893
		IACC Recommended Budget: $5,000,000 over 5 years					

Question 6: Multiyear Funding Table, see Appendix C for a color-coding key and further details.

Question 6: What Does The Future Hold, Particularly For Adults?

IACC Strategic Plan Objectives	Funding						
Year	**2008**	**2009**	**2010**	**2011**	**2012**	**2013**	**Total**
Conduct comparative effectiveness research that includes a cost-effectiveness component to examine community-based interventions, services, and supports to improve health outcomes and quality of life for adults on the ASD spectrum over age 21 by 2018. Topics should include: • Community housing for people with ASD; • Successful life transitions for people with ASD, including from post-secondary education to adult services, employment, sibling relationships, and day programs; and • Meeting the service and support needs of older adults with ASD.	N/A	6.L.C $0 0 projects	6.L.C $774,644 2 projects	6.L.C $0 0 projects	6.L.C $0 0 projects	6.L.C $0 0 projects	$774,644
		IACC Recommended Budget: $6,000,000 over 5 years					
Conduct implementation research to test the results from comparative effectiveness research in real-world settings, including a cost-effectiveness component to improve health outcomes and quality of life for adults over 21 on the ASD spectrum by 2023.	N/A	6.L.D $0 0 projects	6.L.D $0 0 projects	6.L.D $75,000 2 projects	6.L.D $60,000 3 projects	6.L.D $60,000 2 projects	$195,000
		IACC Recommended Budget: $4,000,000 over 5 years					
Not specific to any objective	**6. Core/ Other Activities** $467,683 2 projects	**6. Core/ Other Activities** $159,444 2 projects	**6. Core/ Other Activities** $671,619 3 projects	**6. Core/ Other Activities** $50,000 3 projects	**6. Core/ Other Activities** $830,556 4 projects	**6. Core/ Other Activities** $1,090,239 7 projects	$3,269,541
Reported funding for Question 6*	$9,796,491 9 projects	$1,407,699 7 projects	$6,643,124 34 projects	$4,897,920 35 projects	$3,859,177 34 projects	$3,152,885 27 projects	$29,757,296
Adjusted funding for Question 6†	$527,683 3 projects	$1,407,699 7 projects	$6,643,124 34 projects	$4,897,920 35 projects	$3,859,177 34 projects	$3,152,886 27 projects	$20,488,489

Question 6: Multiyear Funding Table, see Appendix C for a color-coding key and further details.

*The "Reported funding" totals reflect the funding and projects originally coded to this Question of the *Strategic Plan*, as reported in the *Portfolio Analysis Report* corresponding to the year indicated at the top of the column. When reading each column of the table vertically, please note that the projects and funding associated with each objective for 2008 may not add up to the reported funding total at the bottom of the column; this is due to adjustments made to account for revisions in the *Strategic Plan*, which caused the shifting of some objectives to other Questions under the *Plan*. The projects and funding associated with these reclassified objectives are now reflected under the Question in which they appear in the *2011 Strategic Plan*.

†The "Adjusted funding" total reflects funding for projects aligned to objectives in the *2011 IACC Strategic Plan* (the most recent version in which objectives were revised) and incorporates funding for projects that may have been coded differently under previous versions of the *Plan*.

Table 9. Multiyear Funding Table for Question 6.

QUESTION 7

INFRASTRUCTURE AND SURVEILLANCE

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

RESEARCH FOCUS OF QUESTION 7

Question 7 ("What other infrastructure and surveillance needs must be met?") covers the topics of research infrastructure, data sharing, workforce development, ASD surveillance, and communication/dissemination of research findings and evidence-based practices. With 16 objectives, Question 7 has the greatest number of objectives of all seven questions in the *Strategic Plan.*

A word cloud was made using the project titles listed under this question to describe the research funded in Question 7 in 2013 (**Figure 45**). 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 funded in Question 7.

Figure 45. Word cloud representing themes in Question 7 project titles.

ANALYSIS OF 2013 QUESTION 7 PORTFOLIO

Projects assigned to Question 7 comprised 14% ($44.1 million) of the total ASD research supported in 2013. Question 7 consisted of 117 projects, which was 9% of the total number of projects. The agencies and organizations with the largest investments in Question 7 include Simons Foundation, the National Institutes of Health, and the Centers for Disease Control and Prevention. There are 16 objectives that fall under the Question 7 research area. Five objectives did not have active projects or funding in 2013. **Figure 46** provides a detailed overview of each objective's total funding in 2013 as well as the number of projects assigned to each objective.

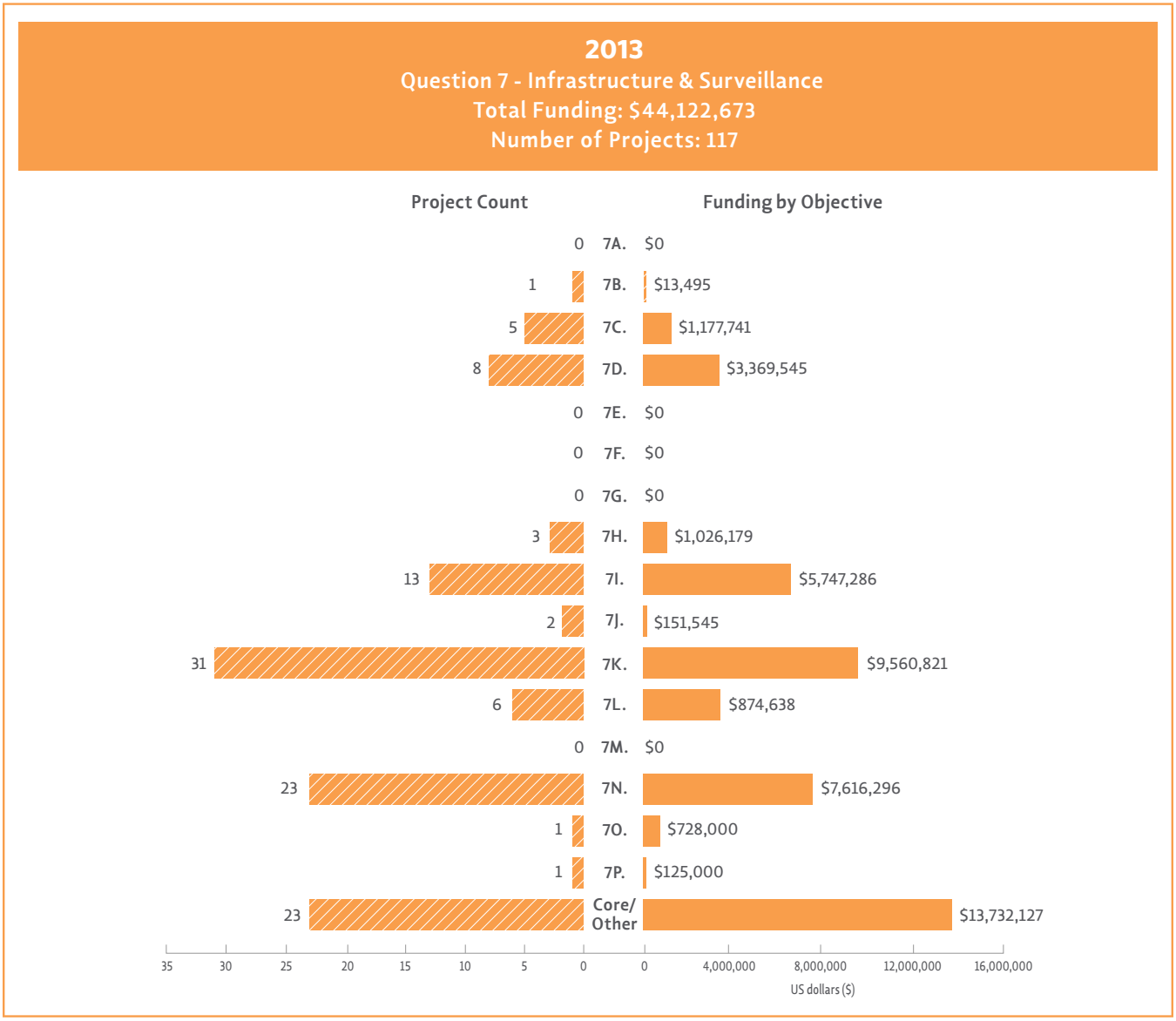


Figure 46. Question 7 objectives broken down by their funding and project count.

The largest portion of funding categorized under Question 7 did not fit into any of the specific research objectives and were assigned as Core/Other ($13.7 million, 31%). Of the 16 Question 7 objectives, programs enhancing the research workforce and developing interdisciplinary training (7.K) received the next largest amount of funding ($9.6 million, 22%). Objective 7.N followed with $7.6 million (17%) in funding and 23 projects; this objective funds the expansion of clinical research sites collecting and coordinating standardized and comprehensive diagnostic, biological, and medical data. Although Objective 7.G was not funded in 2013, it was already considered completed due to activity in previous years. Objectives 7.A, 7.E, 7.F, and 7.M also did not receive any funding in 2013. Objective 7.E, which supports the development of a virtual toolbox for researchers to disseminate findings, has received funding in previous years and is considered complete. However, objectives 7.A, 7.F, and 7.M have never received funding, which may be due to the wording or specificity of the goal (e.g., the "Promising Practices" papers program mentioned in objective 7.M was piloted by CMS prior to the launch of the *Strategic Plan* in 2009, but the program was not continued). **Table 10** lists all the objectives and their progress to date.

QUESTION 7 SUBCATEGORY ANALYSIS

Projects within Question 7 accounted for $44.1 million of total funding in 2013. 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 47**).

The six subcategories in Question 7 encompass a diverse set of project types, with funding distributed relatively evenly across them. In 2013, **Research infrastructure** received 29% of funding, followed by support for **Research workforce development** (22%), which supports conferences and training for autism researchers. **Surveillance and prevalence studies**, such as studies under the Autism and Developmental Disabilities Monitoring (ADDM) Network, and **Data tools**, such as National Database for Autism Research (NDAR) and the Autism Genetics Resource Exchange (AGRE) each received 15% of funding. **Research recruitment and clinical care**, which helps increase participation in research studies and conduct medical evaluations of participants, received 10%, and **Biobanks** received 8%.

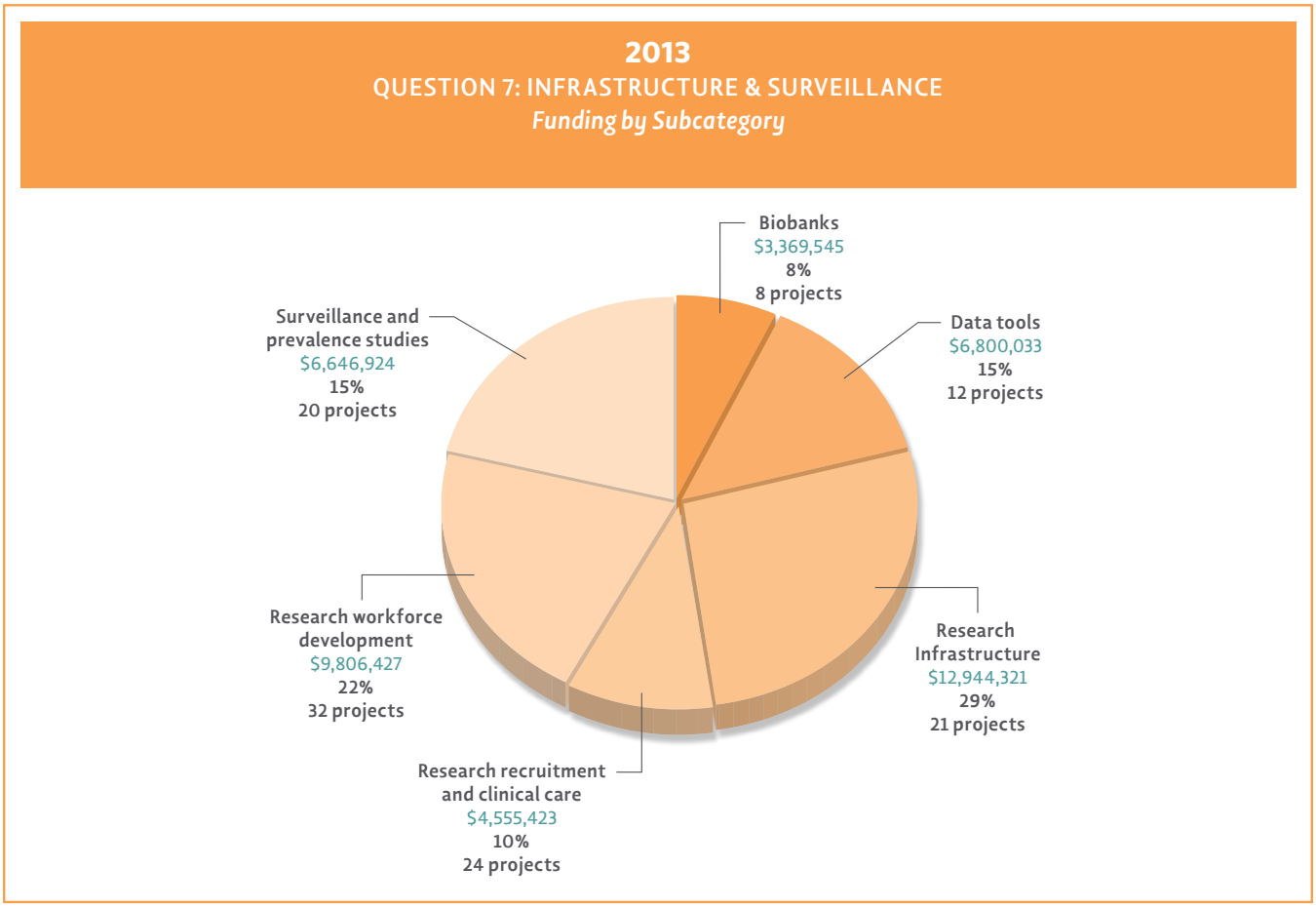


Figure 47. Question 7 funding by subcategory in 2013.

PROGRESS MADE ON QUESTION 7 FROM 2008-2013

Figure 48 shows the trend in Question 7 funding over the six-year span of 2008-2013 using the adjusted funding totals from **Table 10**. The adjusted funding reflects funding for projects aligned to objectives in the *2011 IACC Strategic Plan* and accounts for funding of projects that may have been coded differently under previous versions of the *Plan*. Research falling within this question area experienced a rapid increase in funding from 2008-2010. However, 2010 funding levels for these infrastructure and surveillance projects leveled off to a flat, moderate level from 2010-2013.

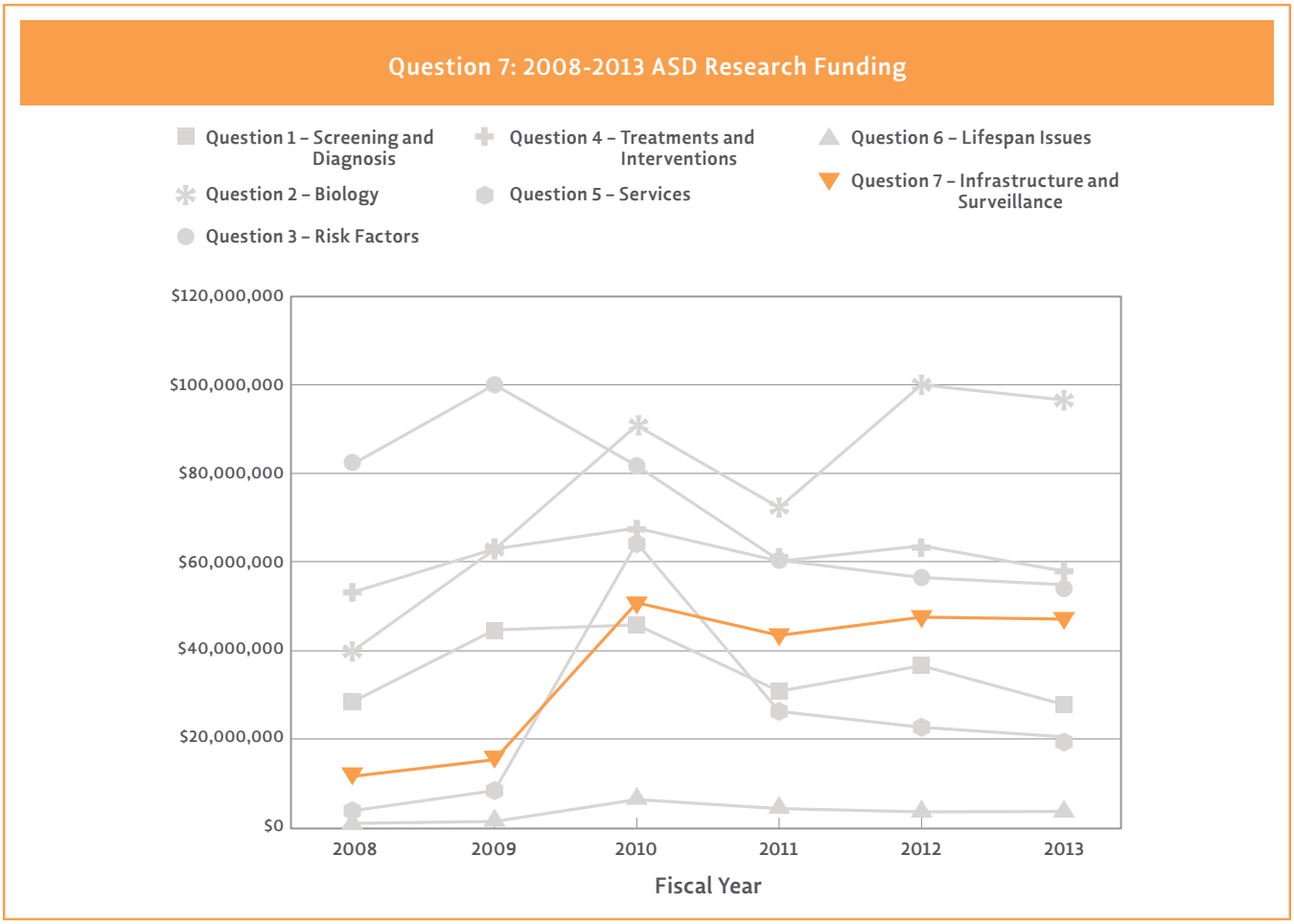


Figure 48. Question 7 ASD research funding from 2008-2013. Following an initial increase from 2008-2010, funding for Question 7 remained primarily flat from 2010-2013.

PROGRESS MADE ON QUESTION 7 OBJECTIVES FROM 2008-2013

An assessment of total progress since 2008 indicates that nine Question 7 objectives were considered completed, four objectives saw partial progress toward their overall recommended budgeted goals, and three objectives —Objectives 7.A (needs assessment toward linkage of administrative databases), 7.F (replication studies), and 7.M (promising practices papers about successful services delivery strategies)—have experienced no progress as of 2013 (**Figure 49**). The Committee felt that 7.A was still a need, but the IACC was uncertain of whether the objective 7.F was feasible, and of whether or not 7.M had been replaced by other modes of dissemination. While a number of Question 7 objectives saw growth in 2013, the 2013 progress was not enough to change the overall status of any of the objectives from what was reported in 2012. **Table 10** provides a snapshot of progress made on all 16 of the research objectives within Question 7 over the period from 2008-2013.

Figure 49. Overall status of progress for the 16 Question 7 objectives.

Question 7: What Other Infrastructure And Surveillance Must Be Met?

IACC Strategic Plan Objectives	Funding						
Year	2008	2009	2010	2011	2012	2013	Total
Conduct a needs assessment to determine how to merge or link administrative and/or surveillance databases that allow for tracking the involvement of people living with ASD in health care, education, and social services by 2009.	6.4 $0 0 projects	7.A $0 0 projects	7.A $0 0 projects	7.A $0 0 projects	7.A $0 0 projects	7.A $0 0 projects	$0
	IACC Recommended Budget: $520,000 over 1 year						
Conduct an annual "State of the States" assessment of existing State programs and supports for people and families living with ASD by 2011.	5.1 $311,670 6 projects	7.B $7,061 1 project	7.B $197,128 1 project	7.B $88,154 1 project	7.B $0 1 project	7.B $13,495 1 project	$617,508
	IACC Recommended Budget: $300,000 each year						
Develop and have available to the research community means by which to merge or link databases that allow for tracking the involvement of people in ASD research by 2010.	6.1 $6,767,808 4 projects	7.C $1,665,180 2 projects	7.C $2,785,368 5 projects	7.C $1,387,146 7 projects	7.C $985,158 6 projects	7.C $1,177,741 5 projects	$14,768,401
	IACC Recommended Budget: $1,300,000 over 2 years						
Establish and maintain an international network of biobanks for the collection of brain tissue, fibroblasts for pluripotent stem cells, and other tissue or biological material, by acquisition sites that use standardized protocols for phenotyping, collection, and regulated distribution of limited samples by 2011. • This includes support for post-processing of tissue, such as genotyping, RNA expression profiling, and MRI. • Protocols should be put into place to expand the capacities of ongoing large-scale children's studies to collect and store additional biomaterials, including newborn bloodspots, promoting detection of biological signatures. • Support should also be provided to develop an international web-based digital brain atlas that would provide high-resolution 3-D images and quantitative anatomical data from tissue of patients with ASD and disease controls across the lifespan, which could serve as an online resource for quantitative morphological studies, by 2014.	2.1 & 2.6 $5,018,579 1 project & 1 project	7.D $436,815 2 projects	7.D $7,814,918 6 projects	7.D $8,531,425 6 projects	7.D $2,950,550 5 projects	7.D $3,369,545 8 projects	$28,121,832
	IACC Recommended Budget: $82,700,000 over 5 years						
Begin development of a web-based toolbox to assist researchers in effectively and responsibly disseminating their findings to the community, including people with ASD, their families, and health practitioners by 2011.	N/A	7.E $330,663 2 projects	7.E $390,134 1 project	7.E $533,354 1 project	7.E $0 1 project	7.E $0 0 projects	$1,254,151
	IACC Recommended Budget: $400,000 over 2 years						
Create funding mechanisms that encourage rapid replication studies of novel or critical findings by 2011.	N/A	7.F $0 0 projects	7.F $0 0 projects	7.F $0 0 projects	7.F $0 0 projects	7.F $0 0 projects	$0
	No recommended budget assigned by the IACC						

Question 7: Multiyear Funding Table, see Appendix C for a color-coding key and further details.

Question 7: What Other Infrastructure And Surveillance Must Be Met?

IACC Strategic Plan Objectives	Funding						
Year	2008	2009	2010	2011	2012	2013	Total
Develop a web-based tool that provides population estimates of ASD prevalence for States based on the most recent prevalence range and average identified by the ADDM Network by 2012. (**This objective can be considered completed – CDC's Environmental Tracking tool**)	N/A	7.G $0 0 projects	7.G $0 0 projects	7.G $0 0 projects	7.G* $0 **0 project**	7.G* $0 **0 project**	$0
		IACC Recommended Budget: $200,000 over 2 years			**This objective was completed in 2012*		
Create mechanisms to specifically support the contribution of data from 90% of newly initiated projects to the National Database for Autism Research (NDAR), and link NDAR with other existing data resources by 2012.	N/A	7.H $1,932,996 2 projects	7.H $2,453,253 3 projects	7.H $1,517,596 1 project	7.H $3,679,808 5 projects	7.H $1,026,179 3 projects	$10,609,832
		IACC Recommended Budget: $6,800,000 over 2 years					
Supplement existing ADDM Network sites to use population-based surveillance data to conduct at least five hypothesis-driven analyses evaluating factors that may contribute to changes in ASD prevalence by 2012.	N/A	7.I $6,715,815 15 projects	7.I $6,137,128 13 projects	7.I $4,928,453 13 projects	7.I $6,028,878 13 projects	7.I $5,747,286 13 projects	$28,457,135
		IACC Recommended Budget: $660,000 over 2 years					
Develop the personnel and technical infrastructure to assist States, territories, and other countries that request assistance describing and investigating potential changes in the prevalence of ASD and other developmental disabilities by 2013.	N/A	7.J $494,449 11 projects	7.J $170,490 4 projects	7.J $545,414 6 projects	7.J $159,610 4 projects	7.J $151,545 2 projects	$1,521,508
		IACC Recommended Budget: $1,650,000 over 3 years					
Encourage programs and funding mechanisms that expand the research workforce, enhance interdisciplinary research training, and recruit early-career scientists into the ASD field by 2013.	N/A	7.K $2,527,472 7 projects	7.K $7,358,427 34 projects	7.K $4,813,286 27 projects	7.K $10,003,091 25 projects	7.K $9,560,821 31 projects	$34,263,097
		IACC Recommended Budget: $5,000,000 over 3 years					
Expand the number of ADDM sites in order to conduct ASD surveillance in children and adults; conduct complementary direct screening to inform completeness of ongoing surveillance; and expand efforts to include autism subtypes by 2015.	N/A	7.L $699,304 2 projects	7.L $1,429,602 8 projects	7.L $705,552 6 projects	7.L $847,002 6 projects	7.L $874,638 6 projects	$4,556,098
		IACC Recommended Budget: $16,200,000 over 5 years					
Support 10 "Promising Practices" papers that describe innovative and successful services and supports being implemented in communities that benefit the full spectrum of people with ASD, which can be replicated in other communities, by 2015.	N/A	7.M $0 0 projects	7.M $0 0 projects	7.M $0 0 projects	7.M $0 0 projects	7.M $0 0 projects	$0
		IACC Recommended Budget: $75,000 over 5 years					
Enhance networks of clinical research sites offering clinical care in real-world settings that can collect and coordinate standardized and comprehensive diagnostic, biological (e.g., DNA, plasma, fibroblasts, urine), medical, and treatment history data that would provide a platform for conducting comparative effectiveness research and clinical trials of novel autism treatments by 2012.	N/A	N/A	7.N $6,662,790 3 projects	7.N $7,419,887 22 projects	7.N $5,270,828 22 projects	7.N $7,616,296 23 projects	$26,969,801
			IACC Recommended Budget: $1,850,000 over 1 year				

Question 7: Multiyear Funding Table, see Appendix C for a color-coding key and further details.

Question 7: What Other Infrastructure And Surveillance Must Be Met?

IACC Strategic Plan Objectives	Funding						
Year	2008	2009	2010	2011	2012	2013	Total
Create an information resource for ASD researchers (e.g., PhenX Project) to share information to facilitate data sharing and standardization of methods across projects by 2013. • This includes common protocols, instruments, designs, and other procedural documents and should include updates on new technology and links to information on how to acquire and utilize technology in development. • This can serve as a bidirectional information reference, with autism research driving the development of new resources and technologies, including new model systems, screening tools, and analytic techniques	N/A	N/A	7.O $605,338 3 projects	7.O $1,070,941 3 projects	7.O $728,000 1 project	7.O $728,000 1 project	$3,132,279
			IACC Recommended Budget: $2,000,000 over 2 years				
Provide resources to centers or facilities that develop promising vertebrate and invertebrate model systems, and make these models more easily available or expand the utility of current model systems, and support new approaches to develop high-throughput screening technologies to evaluate the validity of model systems by 2013.	N/A	N/A	7.P $1,588,780 1 project	7.P $0 0 projects	7.P $0 0 projects	7.P $125,000 1 project	$1,713,780
			IACC Recommended Budget: $1,100,000 over 2 years				
Not specific to any objective	N/A	**7. Core/ Other Activities** $1,000,000 2 projects	**7. Core/ Other Activities** $13,253,709 26 projects	**7. Core/ Other Activities** $12,314,084 18 projects	**7. Core/ Other Activities** $16,863,272 23 projects	**7. Core/ Other Activities** $13,732,127 23 projects	$57,163,192
Reported funding for Question 7*	N/A	**$15,809,755** 46 projects	**$50,847,065** 108 projects	**$43,855,291** 111 projects	**$47,516,197** 112 projects	**$43,022,248** 117 projects	$201,050,556
Adjusted funding for Question 7†	**$12,098,057** 12 projects	**$15,809,755** 46 projects	**$50,847,065** 108 projects	**$43,855,291** 111 projects	**$47,516,197** 112 projects	**$43,022,248** 117 projects	$213,148,614

Question 7: Multiyear Funding Table, see Appendix C for a color-coding key and further details.

*The "Reported funding" totals reflect the funding and projects originally coded to this Question of the *Strategic Plan*, as reported in the *Portfolio Analysis Report* corresponding to the year indicated at the top of the column. When reading each column of the table vertically, please note that the projects and funding associated with each objective for 2008 may not add up to the reported funding total at the bottom of the column; this is due to adjustments made to account for revisions in the *Strategic Plan*, which caused the shifting of some objectives to other Questions under the *Plan*. The projects and funding associated with these reclassified objectives are now reflected under the Question in which they appear in the *2011 Strategic Plan*.

†The "Adjusted funding" total reflects funding for projects aligned to objectives in the *2011 IACC Strategic Plan* (the most recent version in which objectives were revised) and incorporates funding for projects that may have been coded differently under previous versions of the *Plan*.

Table 10. Multiyear Funding Table for Question 7.

SUMMARY AND CONCLUSION

The *2013 ASD Research Funding Portfolio Analysis Report* is the fifth comprehensive annual review of ASD research funding across both the Federal and private sectors. Data were collected from 18 Federal and private funders, including one which was new to the *Portfolio Analysis*. The diverse missions of the different funders are reflected in the ASD research portfolio across the seven questions of the *Strategic Plan*. In 2013, Federal agencies continued to fund three-quarters of ASD research while private organizations contributed a quarter of funding. Among the participating funders, NIH continued to contribute the largest amount of funding toward autism research.

Overall, funding for ASD research among both Federal and private funders totaled $305.6 million and spanned 1,279 projects. With six years of ASD research funding data available, it was possible to continue analyzing funding trends, enabling meaningful observations about the long-term progress of the field of ASD research over the period from 2008-2013. Over the six years, autism research showed a general upward trend in funding, increasing by 38% 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. In 2013, significant progress was made toward completing the objectives in the *2011 Strategic Plan*, with 95% (74 objectives) of the 78 objectives either partially or fully completed. Considering the period from 2008-2013, only 5% (4 objectives) of the *2011 Strategic Plan* objectives were not active at any point across this six-year window. This indicates that the vast majority of priority areas identified in the *Strategic Plan* objectives were deemed by government and private research funders to be worthy of investment and were implemented either partially or fully. While broad implementation efforts across the vast majority of *Strategic Plan* objectives demonstrated commitment of Federal and private funders to pursuing the research areas prioritized by the Committee, many areas of partial funding still left significant gaps that were not filled over this period. Further attention and additional funding may be needed in the future to stimulate and develop more robust research efforts in those areas.

In addition to analysis of progress made on completing the specific research objectives outlined in the *Strategic Plan*, the subcategory classification system, introduced in the *2010 Portfolio Analysis*, continues to provide an alternative perspective on the content of the autism research portfolio. Even with possible future changes in *Strategic Plan* objectives, the subcategory analysis will allow tracking of growth and change in general research areas over time, including the emergence of new fields that attract investment from research funders.

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 this portfolio analysis to provide more detailed information on the autism research landscape for the Committee and community stakeholders.

The annual *ASD Research Funding 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*. The analysis continues to serve as a resource for the Committee, funders, and the broader ASD community to identify and address knowledge gaps, recognize emerging trends and new opportunities, and guide future research priorities 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 Children and Families (ACF)
The mission of ACF is to foster health and well-being by providing Federal leadership, partnership and resources for the compassionate and effective delivery of human services. The ACF autism-related research portfolio includes projects focused on ensuring that effective and culturally appropriate developmental screening tools and interventions are being developed and deployed in early education settings.

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.

Centers for Medicare & Medicaid Services (CMS)
CMS administers the Medicare program and works in partnership with State governments to administer Medicaid, the State Children's Health Insurance Program (SCHIP), and health insurance portability standards. CMS funds studies to evaluate ASD service provision, access, and coverage, and has commissioned several reports on state-provided services for ASD.

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. 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.

The U.S. Air Force **(DOD-AF)** also funds research on ASD, and is developing a multidisciplinary autism research and services program for military families, part of which involves the creation of a comprehensive registry to provide higher quality data for autism clinical and genetics research.

Department of Education (ED)

The mission of the U.S. Department of Education is to promote student achievement by fostering educational excellence and ensuring equal access. The department funds a portfolio of ASD-related projects relating to development and delivery of educational interventions and services, particularly for children and transition-aged youth. A large portion of ED's funding goes towards developing practitioner training as well as investment in training researchers.

Environmental Protection Agency (EPA)

The mission of the U.S. EPA is to protect human health and the environment. EPA co-funds the Center for Children's Environmental Health (CCEH) at the University of California at Davis with the National Institute of Environmental Health Sciences (NIEHS)/NIH, which conducts research into how environmental exposure to toxins might interact with a person's genes and immune system to influence the 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 Speaks (AS)

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

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 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.

Brain & 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.

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.

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.

NATIONAL SCIENCE FOUNDATION (NSF)

AWARD PERIOD	PRINCIPAL INVESTIGATOR	PROJECT TITLE	WEBLINK
2013-2015	Fuh-Cherng Jeng	Development of Experience-Dependent Responses to Voice Pitch in Newborns and Infants	http://www.nsf.gov/awardsearch/showAward?AWD_ID=1250700&HistoricalAwards=false
2013-2017	Michael Paradiso	Neural investigation of the dual role of saccadic eye movements in visual perception	http://www.nsf.gov/awardsearch/showAward?AWD_ID=1261433&HistoricalAwards=false
2013-2018	Nicole Rust	CAREER: The neural mechanisms underlying visual target and task switching	http://www.nsf.gov/awardsearch/showAward?AWD_ID=1265480&HistoricalAwards=false
2013-2015	Peter Heeman	RI: Small: Flexible Turn-Taking for Mixed-Initiative Spoken Dialogue System	http://www.nsf.gov/awardsearch/showAward?AWD_ID=1321146&HistoricalAwards=false
2013-2016	Paula Niedenthal	Behavioral and neural bases of the perception of facial expressions	http://www.nsf.gov/awardsearch/showAward?AWD_ID=1251101&HistoricalAwards=false
2013-2016	Alison Gopnik	Rational randomness: Search, sampling and exploration in children's causal learning	http://www.nsf.gov/awardsearch/showAward?AWD_ID=1331620&HistoricalAwards=false

2013-2016	Yang Liu	EAGER: Investigating the Role of Discourse Context in Speech-Driven Facial Animations	http://www.nsf.gov/awardsearch/showAward?AWD_ID=1352950&HistoricalAwards=false
2013-2016	Brian Megerko	HCC: Small: Social Agents and Robots for Open-Ended Domains	http://www.nsf.gov/awardsearch/showAward?AWD_ID=1320520&HistoricalAwards=false
2013-2015	Daniel Messinger	Gaze Durations in Infancy	http://www.nsf.gov/awardsearch/showAward?AWD_ID=1323927&HistoricalAwards=false
2013-2017	Emanuel Papadaki	Sparse 3D-Data Representations from Compactly Supported Atoms for Rigid Motion Invariant Classification with Applications to Neuroscience Imaging	http://www.nsf.gov/awardsearch/showAward?AWD_ID=1320910&HistoricalAwards=false
2013-2016	Ivan Soltesz	US-French Collaboration: Mechanisms of emergent OscillaTIONs in the septo-hippocampal network-MOTION	http://www.nsf.gov/awardsearch/showAward?AWD_ID=1310378&HistoricalAwards=false

DEPARTMENT OF EDUCATION, INSTITUTE OF EDUCATION SCIENCES (IES)

AWARD PERIOD	PRINCIPAL INVESTIGATOR	PROJECT TITLE	WEBLINK
2008-2017	Gail Mulligan	Early Childhood Longitudinal Study, Kindergarten Class of 2010-11	http://nces.ed.gov/ecls/kindergarten2011.asp
2007-2015	Steven Ingels	(RTI) High School Longitudinal Study	http://nces.ed.gov/surveys/hsls09
Ongoing	Drew Malizio	National Assessment of Educational Progress	http://nces.ed.gov/nationsreportcard/aboutnaep.asp
2007-2013	Thomas Fiore	Evaluation of the IDEA Personnel Development Program	http://ies.ed.gov/ncee/projects/evaluation/disabilities_personnel.asp

2010-2015	Jose Blackorby	Study of Early Intervention and Special Education Personnel and Services	http://ies.ed.gov/ncee/projects/evaluation/disabilities_persserv.asp
2010-2015	John Burghardt	National Longitudinal Transition Study 2012	http://ies.ed.gov/ncee/projects/evaluation/disabilities_ideatrans.asp
2008-2013	Mengli Song	Study of School Accountability for Students with Disabilities	http://ies.ed.gov/ncee/projects/evaluation/disabilities_students.asp
2009-2014	Tamara Daley	National Evaluation of the IDEA Technical Assistance and Dissemination Program	http://ies.ed.gov/ncee/projects/evaluation/disabilities_idea2004.asp
2007-2013	Jill Constantine, Neil Seftor, Scott Cody	What Works Clearinghouse	http://ies.ed.gov/ncee/wwc/interventionreport.aspx?sid=295
2007-2013	Jill Constantine, Neil Seftor, Scott Cody	What Works Clearinghouse	http://ies.ed.gov/ncee/wwc/SingleStudyReview.aspx?sid=10011
2007-2013	Jill Constantine, Neil Seftor, Scott Cody	What Works Clearinghouse	http://ies.ed.gov/ncee/wwc/topic.aspx?sid=19
2012-2014	Bonnie Doren, Christopher Murray, Ketih Zvoch	Examining malleable factors associated with school and post-school outcomes of economically disadvantaged youth with disabilities: A secondary analysis of data from the National Longitudinal Transition Study (NLTS2)	http://ies.ed.gov/funding/grantsearch/details.asp?ID=1242
2011-2014	Karrie Shogren	Exploring the predictors and outcomes of self-determination for secondary students with disabilities using NLTS2	http://ies.ed.gov/funding/grantsearch/details.asp?ID=1100

APPENDIX C

ASD Research Progress on *IACC Strategic Plan* Objectives: Summary of Years 2008-2013

The tables include data (project numbers and funding) from Federal and private funders of ASD research for years 2008 through 2013, as aligned with the objectives of the *2011 IACC Strategic Plan*. Please note the following:

During the updating of the *Strategic Plan* from 2008-2010, the wording and numbering of objectives changed. Data included in each *Portfolio Analysis Report* from 2008-2013 was categorized at the time with respect to the most recent iteration of the *Strategic Plan* where the objectives had changed. For the purpose of this six-year comparison, data from the *Portfolio Analyses* conducted in 2008 and 2009 were aligned with the most recent objectives, found in the *2011 Strategic Plan*. The full wording of the 78 objectives listed in the *2011 Strategic Plan* is depicted in the left column of the table.

The middle six columns of the table contain the data (project numbers and funding) for each individual year from 2008-2013, with the objective number (as it appeared in the annual *Portfolio Analysis*) listed above it. The format of objective numbers are abbreviations representing the question number (indicated by a numeral 1-7), whether the objective is a short- or long-term objective (indicated by the letter "S" or "L", respectively), and the objective designation (indicated by a letter). The IACC recommended budget listed below the project data represents the most updated budget listed in the *2011 Strategic Plan*. If the recommended budget has been revised since 2008, the year the revision took place is found in parentheses following the budget figure. Therefore, if there is no mention of a revision, the IACC recommended budget has remained constant from 2008-2011. The annual project status for each objective from 2008-2013 is indicated within the table by colored highlighting of the objective number. An objective is considered active if its status is green or yellow, and inactive if its status is red.

- Any objective colored green has funding which is greater than or equal to the recommended funding for that year (determined by annualizing the recommended budget associated with that objective); any objective colored yellow has actively funded projects, but with funding that totals less than the annualized recommended amount; any objective colored red has no active, funded projects.[3]
- Objectives whose overarching aim (e.g., the ultimate goal of the research, irrespective of the number of projects or the budget for the objective) were achieved/partially achieved either in a previous year, with less annual funding than was recommended, or with funding that was not captured in the portfolio analyses,[4] are colored pale green/pale yellow.

[3]Please note that while the green, yellow, and red indicators suggest a funding status for each year and that looking across all years may give some indication of a trend, some agencies and organizations provide all the funding for multiyear grants in a single year, resulting in the appearance of "less funding" in other years; projects completing the objectives may still have been ongoing in the years where the funding appears to be less. Thus, it is important to note the numbers of projects in looking across the chart, and to keep in mind that in a series, where, for example, most of the indicators are green, that the objective is likely to be largely "complete" according to the funding-based measure.

[4]Reasons why funding for certain projects may not have been captured in the portfolio analyses include projects that were supported by funding that was not specific for autism (i.e., projects that benefited autism but were supported by general neuroscience or developmental disorder funding) or projects supported by funders that did not participate in the portfolio analysis in a given year.

The far right column of the table lists the sum of the total funding aligned with each objective from 2008-2013. Highlighting of each total gives an indication of the overall progress toward completing each objective.

- Green highlighting indicates that funding fully meets the recommend budget. Yellow highlighting denotes that funding for a particular objective partially meets the IACC recommended budget, while red highlighting indicates that there has been no funding towards the particular objective.
- Objectives whose overarching aim (e.g. the ultimate goal of the research, irrespective of the number of projects or the budget for the objective) was achieved/partially achieved either with a lower funding level than was recommended or with funding that was not captured in the portfolio analyses, are colored pale green/pale yellow.

APPENDIX D

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, telecon-ferencing, 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 (27 projects in 2013) and the significant overlap between topics covered in these projects, no subcategories were created for this question in the *2013 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.

Research infrastructure
This subcategory includes coordinating centers that support multiple research projects by running tests, analyzing data, and providing statistical analyses. 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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