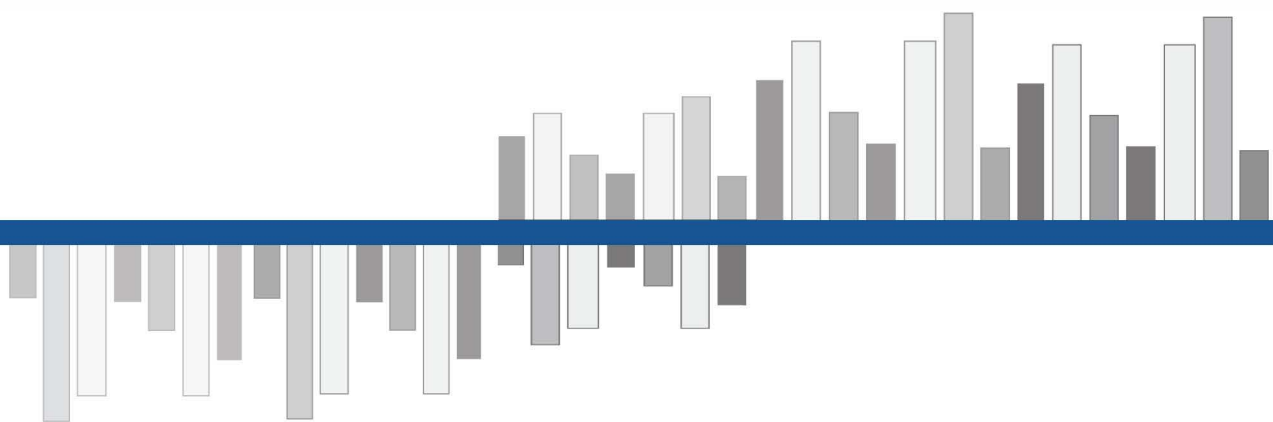


Autism Spectrum Disorder Research

2008 Portfolio Analysis Report

Prepared by the Office of Autism Research Coordination



The Interagency Autism Coordinating Committee

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2008 Portfolio Analysis of Autism Spectrum Disorder (ASD) Research Funding

Introduction

In 2009, the Interagency Autism Coordinating Committee (IACC) conducted a comprehensive analysis of the 2008 autism spectrum disorder (ASD) research portfolios of major Federal agencies and private organizations. The analysis was conducted to better inform the committee and interested public about the funding landscape for ASD research and how well this matched the new IACC Strategic Plan for ASD research. In so doing, the portfolio analysis also can be used by Federal agencies and private research organizations to help guide future funding priorities by highlighting current gaps and opportunities in ASD research as well as serving as a baseline to assess research progress.

Who funded ASD research in 2008?

The Office of Autism Research Coordination (OARC), on behalf of the IACC, asked Federal agencies and private organizations for information about the ASD-related research grants that they supported in 2008, including the annual budget of each project and its relevance to the six questions of the 2009 IACC Strategic Plan for ASD Research (e.g., When Should I Be Concerned? How Can I Understand What Is Happening? What Caused This To Happen and Can It Be Prevented? Which Treatments and Interventions Will Help? Where Can I Turn For Services? What Does the Future Hold?). Nineteen ASD stakeholders were approached for funding information ([Figure 1](#)). Of those, 13 reported that they had funded ASD research in 2008. The remaining six were funding service programs or other non-research activities, rather than ASD

research [Table 1](#) lists the 19 Federal agencies and private organizations approached for the portfolio analysis and notes whether or not each stakeholder funded ASD research in 2008.

Organizations Included in the 2008 IACC Portfolio Analysis of ASD Research Funding

Federal Agencies	Private Organizations
• Administration for Children and Families (ACF)* • Agency for Healthcare and Research Quality (AHRQ)* • Centers for Disease Control and Prevention (CDC) • Centers for Medicare and Medicaid Services (CMS) • Department of Defense (DoD) • Department of Education (ED) • Department of Housing and Urban Development (HUD)* • Health Resources and Services Administration (HRSA) • National Institutes of Health (NIH) • Social Security Administration (SSA)* • Substance Abuse & Mental Health Services Administration (SAMHSA)*	• Autism Consortium • Autism Speaks • Autism Research Institute (ARI) • Center for Autism and Related Disabilities • The Doug Flutie Jr. Foundation for Autism* • Organization for Autism Research (OAR) • Southwest Autism Research and Resource Center (SARRC) • The Simons Foundation (Simons)

* Indicates organizations that reported that they had not funded ASD research in 2008.

Table 1. The table lists the nineteen Federal agencies and private organizations included in the 2008 analysis of ASD research funding and indicates whether the organization funded ASD research during the year. Six of the eleven Federal agencies that were approached for the portfolio analysis reported funding ASD research, as did seven of the eight private organizations.

What was the basic breakdown of funding?

The 13 stakeholders that funded ASD research in 2008 contributed a total of \$222,215,342 across 745 projects ([Table 2](#)). The average funding per project varied greatly between organizations, ranging from \$24,643 to \$2,030,264, with some organizations choosing to support a few large projects while others distributed funds across several smaller projects. The National Institutes of Health (NIH) contributed the largest amount of research funding in 2008, spending \$117,969,770 on 340 projects, followed by the Simons Foundation with 77 projects

totaling \$42,985,684. Autism Speaks ranked third with \$30,828,116 spent across 200 projects.

In the split between Federal and private funding, the Federal government supported about two-thirds of the total research budget, while private organizations funded the remaining one-third ([Figure 1](#)).

2008 ASD Research Funding by Funding Agency/Organization

Funding Agency/Organization*	Number of Projects	Average Funding Per Project	Total Funding
National Institutes of Health	340	\$346,970	\$117,969,770
Simons Foundation	77	\$558,256	\$42,985,684
Autism Speaks	200	\$154,141	\$30,828,116
Centers for Disease Control and Prevention	27	\$682,855	\$15,022,812
Health Resources and Services Administration	3	\$2,030,264	\$6,090,792
Department of Education	7	\$491,292	\$3,439,047
Autism Consortium	22	\$100,683	\$2,215,017
Department of Defense	8	\$147,223	\$1,177,781
Center for Autism and Related Disorders	26	\$31,369	\$815,581
Organization for Autism Research	16	\$45,625	\$730,000
Autism Research Institute	13	\$40,085	\$521,099
Southwest Autism Research & Resource Center	5	\$79,000	\$395,000
Centers for Medicare and Medicaid Services	1	\$24,643	\$24,643
Grand Total	745	\$300,291	\$222,215,342

*Research projects included are those identified by the agencies and organizations as funded in the most recent 12 months for which data were available. 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 RePORTER system, where each co-fund is counted as a separate project.

Table 2. The table lists the total funding provided by the agencies and organizations included in the portfolio analysis, the number of projects funded, and the average funding per project. Together, the agencies and organizations funded 745 projects at an average of \$300,291 per project.

Comparison of Federal versus Private Funding for ASD Research in 2008

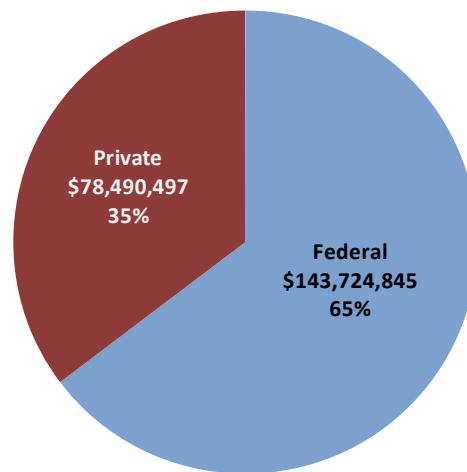


Figure 1. Sixty-five percent of the \$222 million spent on ASD research in 2008 came from Federal sources, while thirty-five percent of funding came from private organizations.

What ASD research was done?

To better understand what areas of research were funded in 2008, projects were mapped to the corresponding questions in the 2009 Strategic Plan. [Figure 2](#) illustrates the breakdown of the research funding according to the Plan's six questions related to diagnosis, biology, risk and protective factors, treatments, services, and lifespan issues. Identifying how current research investments correspond to the Plan will help to understand the current main areas of focus in the field, as well as areas that are currently underdeveloped. In 2008, the largest proportion of research funding (37%) related to the question of ASD causation: "What Caused This to Happen and Can It Be Prevented?" Research on treatments and interventions received the next largest investment with 24% of total funding. Understanding the underlying biology of ASD received 18% of funding and research addressing diagnosis received 13%. The two areas of the Plan that

received the least amount of funding related to services research (1%) and research on lifespan issues (“What Does the Future Hold”), which includes transitioning into adulthood (5%).

2008 ASD Research Funding by Topic Area (Defined as Questions in the 2009 Strategic Plan)

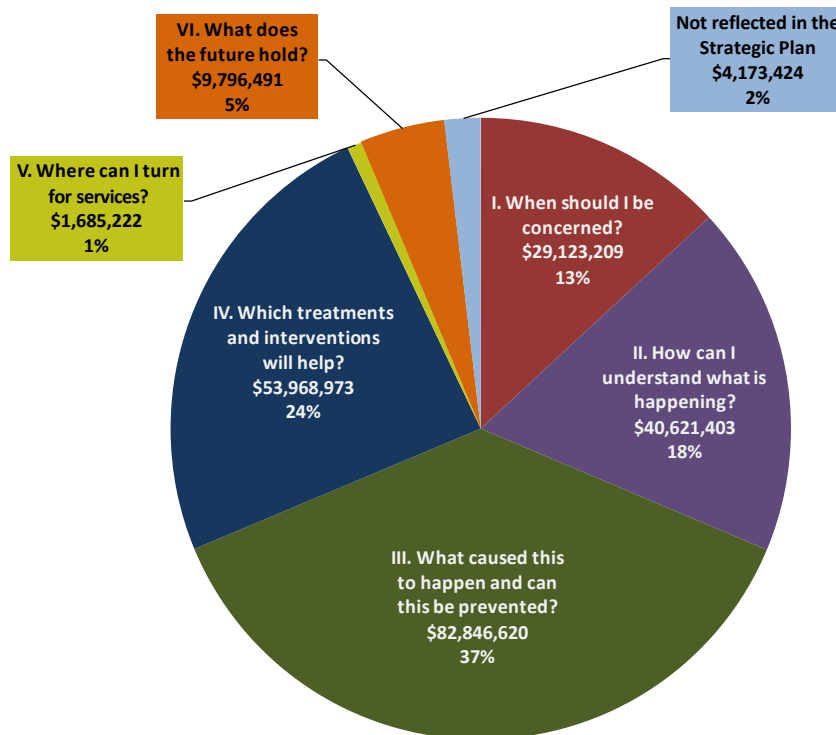


Figure 2. In 2008, the largest proportion of research funding (thirty-seven percent) was devoted to risk factors for ASD reflected in the question: “What Caused This to Happen and Can It Be Prevented?” Twenty-four percent of the research addressed interventions and treatments, eighteen percent related to the underlying biology of ASD, and thirteen percent related to diagnosis. Research on services and lifespan issues received the smallest proportion of funding.

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

After assessing the distribution of research funding across the Strategic Plan questions, the IACC analyzed how well the 2008 research addressed the specific goals outlined in the Plan’s 40 research objectives. Each question in the Plan has several long and short-term objectives calling for specific research projects with a goal date and an estimate of the budget required to

accomplish the goal. For example, the first objective in Question 1: “When Should I Be Concerned?” calls for the development of “at least one efficient diagnostic instrument that is valid in diverse populations for use in large-scale studies by 2011,” with a recommended budget of \$5,300,000 over two years.

[Figure 3](#) illustrates how much of the 2008 funding addresses specific objectives in the Plan.

Each Plan question is represented by a bar; the blue portion illustrates the amount of funding within the question that went towards research aligned with one of the objectives. The red portion represents research that relates to the topic area of the question (e.g., diagnosis, biology, risk factors, etc.), but is not specific to any of the objectives. As an example, a research project studying how children with ASD process the visual information that accompanies speech has implications for diagnosis, however it does not relate to a specific objective in Question 1. This would be classified as Question 1 research “not specific to objectives.”

2008 ASD Research Funding by Strategic Plan Question: Specific versus Not Specific to Research Objectives

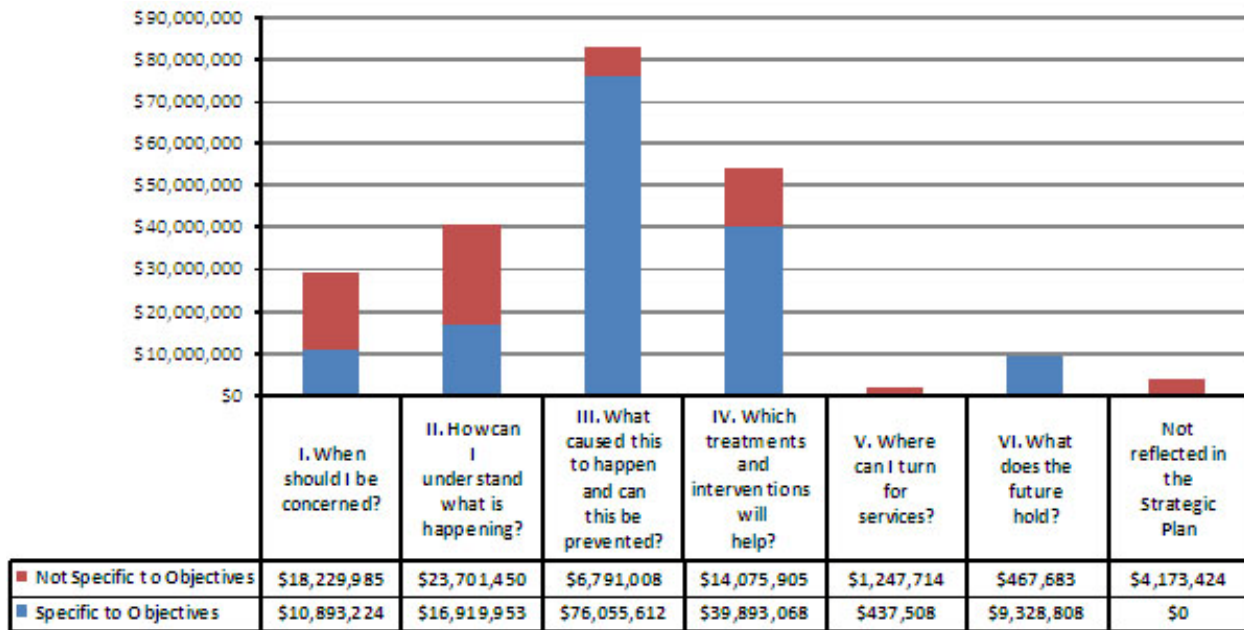


Figure 3. The bar chart shows the amount of ASD funding that aligned with objectives in the Strategic Plan. The blue sections represent research that fulfilled Plan objectives, while the red sections represent research within the question topic area that fell outside the specific projects called for in the objectives. Research related to Questions 3 and 6 – risk factors and lifespan issues – had the highest proportion of projects that aligned with objectives.

Of the six questions, Question 6 – which relates to issues over the lifespan – had the largest proportion of research aligned with an objective (95% of the total \$9.8 million in funding). This was followed by Question 3 on risk factors, with 92% of the \$82.8 million in research corresponding to an objective. Conversely, more than half of the funding devoted to Question 1: “When Should I Be Concerned?” and Question 2: “How Can I Understand What is Happening?” was for projects outside the focus of the objectives.

When examining only Federal funding, the distribution of objective-specific research is strikingly similar to that of the combined Federal and private funding ([Figure 4](#)). The vast majority of research related to Questions 3 and 6 is specific to Plan objectives, while Questions 1 and 2 show the opposite pattern.

**2008 Federal Funding of ASD Research by Strategic Plan Question:
Specific versus Not Specific to Research Objectives**

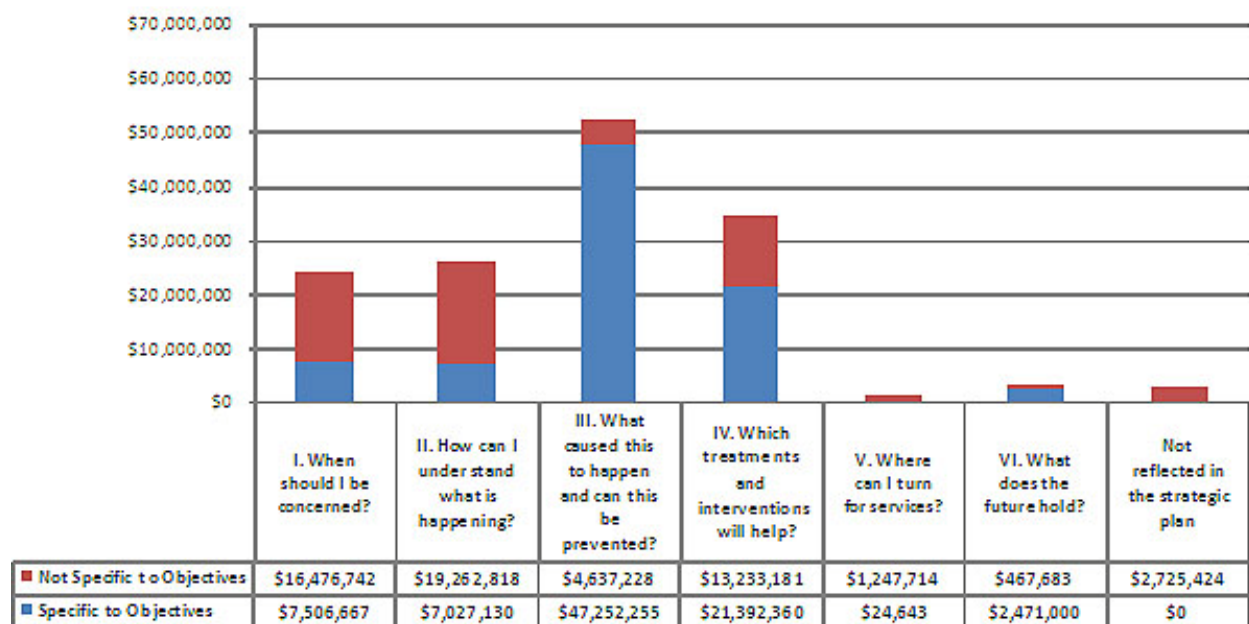


Figure 4. Federal funding of ASD research in 2008 showed a similar pattern to overall funding – research related to risk factors and lifespan issues most closely aligned with the Plan objectives, while more than half of the research related to diagnosis and biology did not align with stated objectives.

Conclusion

The 2008 ASD research funding portfolio analysis is the first comprehensive review of ASD research funding across both the public and private sector and provides a valuable snapshot of the current funding landscape. This initial analysis will serve as the baseline for future analyses

of ASD research funding to be conducted annually as part of the updating process for the IACC Strategic Plan for Autism Spectrum Disorder Research. Trends identified during the analysis can be used to address underfunded areas, identify new research opportunities and priorities, and guide the direction of future research.

More information on the breakdown of 2008 ASD research funding, including the total funding for each objective in the 2009 IACC Strategic Plan for Autism Spectrum Disorder Research, can be found at:

http://iacc.hhs.gov/events/2010/2008_portfolioanalysis_revised.pdf

INTERAGENCY AUTISM COORDINATING COMMITTEE MEMBER ROSTER**CHAIR****Thomas R. Insel, M.D.**

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National Institutes of Health
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Eunice Kennedy Shriver National Institute
of Child Health and Human Development
National Institutes of Health
Bethesda, MD

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Associate Division Director
Research-to-Practice Division
Early Childhood Programs
Office of Special Education Programs
U.S. Department of Education
Washington, DC

Larke N. Huang, Ph.D.

Senior Advisor on Children
Office of the Administrator
Substance Abuse and Mental Health Services
Administration
Rockville, MD

Jennifer G. Johnson, Ed.D.

Program Specialist
Administration on Developmental
Disabilities
Administration for Children and Families
Washington, DC

Walter J. Koroshetz, M.D.

Deputy Director
National Institute of Neurological
Disorder and Stroke
National Institutes of Health
Bethesda, MD

Edwin Trevathan, M.D., M.P.H.

Director, National Center on Birth Defects and
Developmental Disabilities
Centers for Disease Control and Prevention
Atlanta, GA

Peter van Dyck, M.D., M.P.H.

Associate Administrator
Maternal and Child Health
Health Resources and Services Administration
Rockville, MD

PUBLIC MEMBERS**Lee Grossman**

President and CEO
Autism Society of America
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Autism Spectrum Consulting
Newton, MA

Alison Tepper Singer, M.B.A.

President
Autism Science Foundation
New York, NY

NIH/NIMH OFFICE OF AUTISM RESEARCH COORDINATION STAFF

6001 Executive Boulevard, Room 8185, Bethesda, MD 20892

Email: IACCPublicInquiries@mail.nih.gov

Della M. Hann, Ph.D.

Acting Director

Susan A. Daniels, Ph.D.

Deputy Director

Erin H. Bryant, M.J.

Science Writer/Editor

Nicole Jones

Web Developer

Monica P. Mallampalli, Ph.D.

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Detailer, NIMH Intramural Research Program

