

Update on New IACC Publications and the Combating Autism Act *Report to Congress*

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2011 IACC Strategic Plan

The Interagency Autism Coordinating Committee

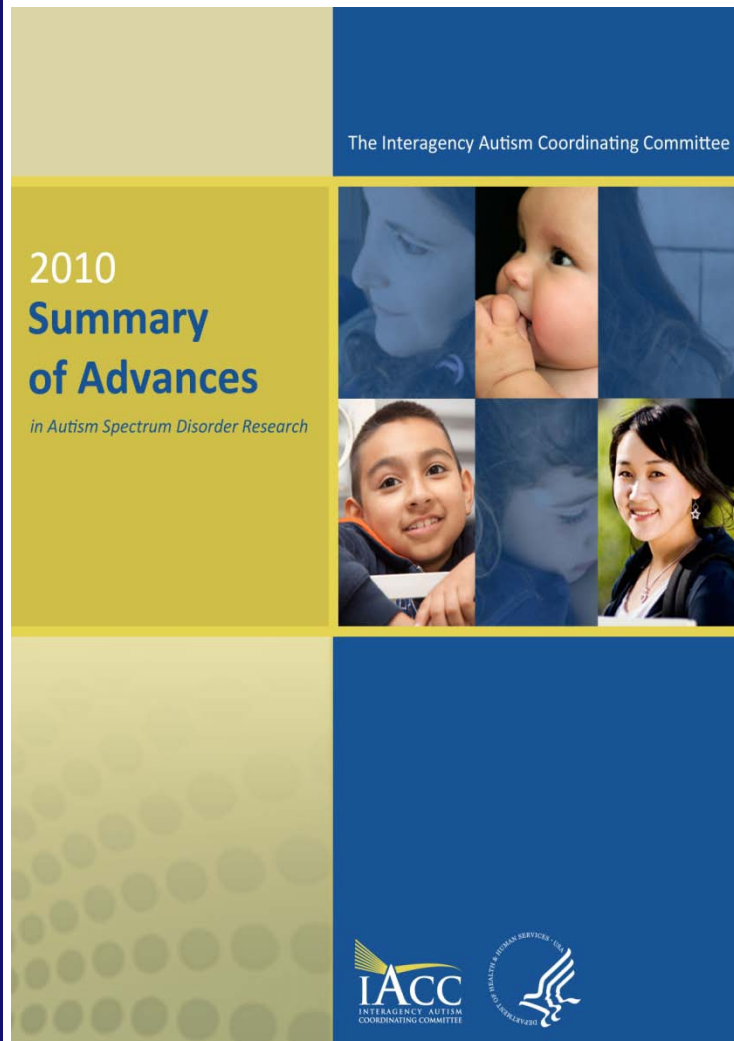
2011 STRATEGIC PLAN

for Autism Spectrum Disorder Research



- Sixteen new objectives were added in 2011, resulting in 78 total research objectives spread across the seven questions framing the Plan
- New areas of focus for the Plan include:
 - Studies on the use and accessibility of Alternative and Augmentative Communication (AAC) tools for nonverbal individuals
 - Prevention of related health concerns such as obesity and mental health issues
 - Understanding safety issues that may increase risk of injury or endanger life

2010 Summary of Advances



- The IACC identified 20 research findings and associated peer-reviewed articles published in 2010 that they felt reflected the most significant advances in ASD biomedical and services research.
- These studies gave important new insight into the prevalence of autism spectrum disorder, the biology of the disorder, potential risk factors, possible interventions, and services needs.

2010 Summary of Advances Selected Articles

Question 1: When should I be concerned?

- **Implementing developmental screening and referrals: lessons learned from a national project.** (King et al., *Pediatrics*)
- **Consensus statement: Chromosomal microarray is a first-tier clinical diagnostic test for individuals with developmental disabilities or congenital anomalies.** (Miller et al., *American Journal of Human Genetics*)
- **Automated vocal analysis of naturalistic recordings from children with autism, language delay, and typical development.** (Oller et al., *Proceedings of the National Academy of Science USA*)
- **A prospective study of the emergence of early behavioral signs of autism.** (Ozonoff et al., *Journal of the American Academy of Child and Adolescent Psychiatry*)

2010 Summary of Advances Selected Articles

Question 2: When should I be concerned?

- **Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs: a consensus report.** (Buie et al., *Pediatrics*) and **Recommendations for evaluation and treatment of common gastrointestinal problems in children with ASDs.** (Buie et al., *Pediatrics*)
- **Describing the brain in autism in five dimensions – magnetic resonance imaging-assisted diagnosis of autism spectrum disorder using a multiparameter classification approach.** (Ecker et al., *Journal of Neuroscience*)
- **Mitochondrial dysfunction in autism.** (Giulivi et al., *Journal of the American Medical Association*)
- **Neural signatures of autism.** (Kaiser et al., *Proceedings of the National Academy of Science USA*)

2010 Summary of Advances Selected Articles

Question 2: When should I be concerned?

- **A model for neural development and treatment for Rett syndrome using human induced pluripotent stem cells.** (Marchetto et al., *Cell*)
- **Longitudinal MRI study of cortical development through early childhood in autism.** (Schumann et al., *Journal of Neuroscience*)

2010 Summary of Advances Selected Articles

Question 3: What caused this to happen and can it be prevented?

- **Mutations in the SHANK2 synaptic scaffolding gene in autism spectrum disorder and mental retardation.** (Berkel et al., *Nature Genetics*)
- **Blood mercury concentrations in CHARGE Study children with and without autism.** (Hertz-Picciotto et al., *Environmental Health Perspectives*)
- **Functional impact of global rare copy number variation in autism spectrum disorders.** (Pinto et al., *Nature*)
- **Altered functional connectivity in frontal lobe circuits is associated with variation in the autism risk gene CNTNAP2.** (Scott-Van Zeeland et al., *Science Translational Medicine*)

2010 Summary of Advances Selected Articles

Question 4: Which treatments and interventions will help?

- **Randomized, controlled trial of an intervention for toddlers with autism: The Early Start Denver Model.** (Dawson et al., *Pediatrics*)
- **Randomized controlled caregiver mediated joint engagement intervention for toddlers with autism.** (Kasari et al., *Journal of Autism and Developmental Disorders*)
- **Evaluation of comprehensive treatment models for individuals with autism spectrum disorders.** (Odom et al., *Journal of Autism and Developmental Disorders*)
- **Evidence-based practices in interventions for children and youth with autism spectrum disorders.** (Odom et al., *Preventing School Failure*)

2010 Summary of Advances Selected Articles

Question 5: Where can I turn for services?

- **Can state early intervention programs meet the increased demand of children suspected of having autism spectrum disorders?** (Wise et al., *Journal of Developmental & Behavioral Pediatrics*)

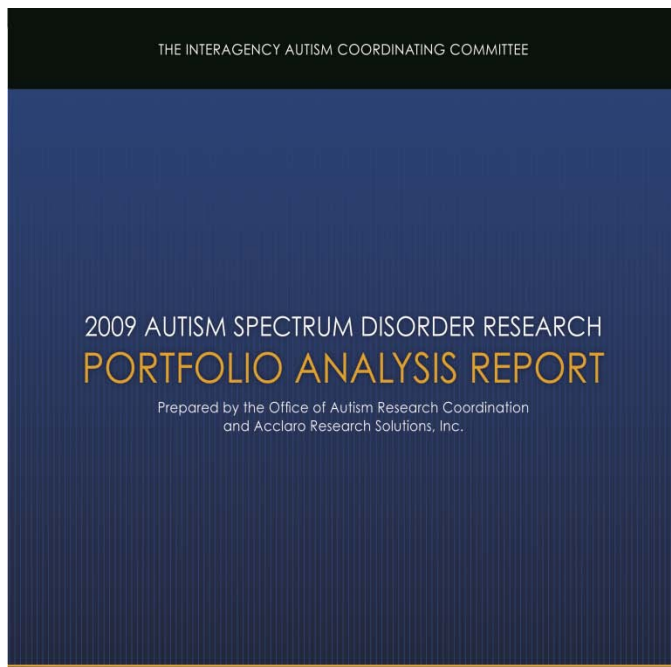
Question 6: What does the future hold, particularly for adults?

- While no articles directly related to this question were selected by the committee, three articles were nominated in this category.

Question 7: What other infrastructure and surveillance needs must be met?

- **Changes in autism spectrum disorder prevalence in 4 areas of the United States.** (Rice et al., *Disability and Health Journal*)

2009 IACC Portfolio Analysis



- Assists the IACC in fulfilling the CAA requirement to monitor Federal activities related to Autism Spectrum Disorder (ASD)
- Provides comprehensive analysis of the ASD research portfolio across both Federal agencies and private organizations
- Informs the IACC and stakeholders about the funding landscape and current directions in ASD research
- Helps the IACC monitor progress in fulfilling the objectives of the IACC Strategic Plan
- Highlights gaps and opportunities to guide future activities

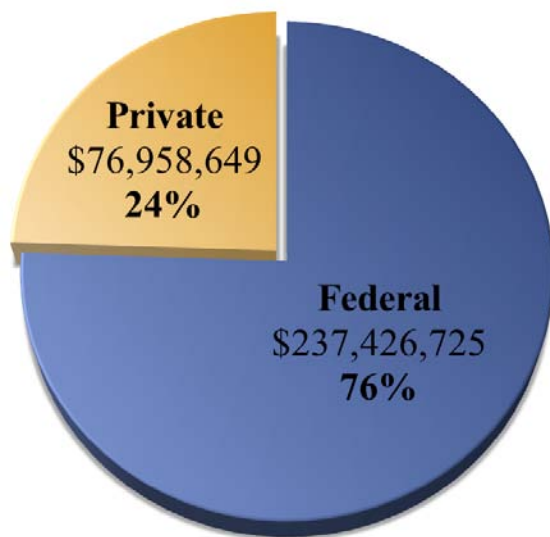
2009 ASD Research Funding by Agency/Organization

Funding Agency/Organization	Number of Projects	Total Funding
National Institutes of Health (NIH)	516	\$196,589,824
The Simons Foundation (SF)	98	\$51,526,058
Autism Speaks (AS)	220	\$23,416,615
Centers for Disease Control and Prevention (CDC)	28	\$19,229,994
Health Resources and Services Administration (HRSA)	9	\$8,097,807
Department of Defense (DoD)	43	\$7,185,010*
Department of Education (ED)	11	\$6,317,029
Center for Autism and Related Disorders (CARD)	29	\$850,594
Autism Research Institute (ARI)	15	\$370,382
Organization for Autism Research (OAR)	14	\$330,000
Southwest Autism Research & Resources Center (SARRC)	5	\$285,000
Autism Science Foundation (ASF)	6	\$180,000
Centers for Medicare & Medicaid Services (CMS)	1	\$7,061
GRAND TOTAL	995	\$314,385,374

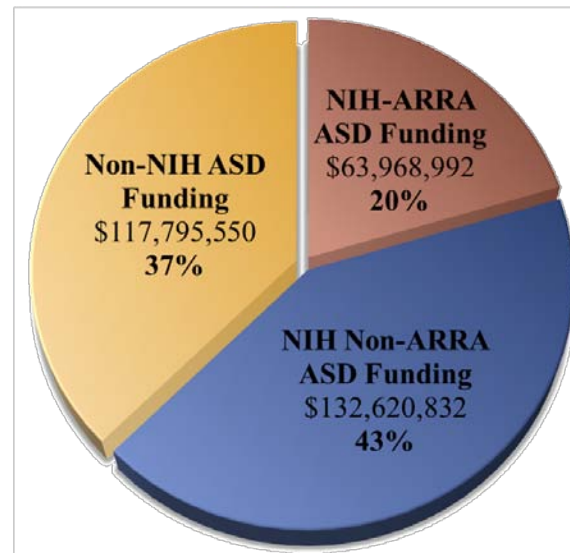
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Total ASD Research Funding

Federal vs. Private Funding for ASD Research in 2009

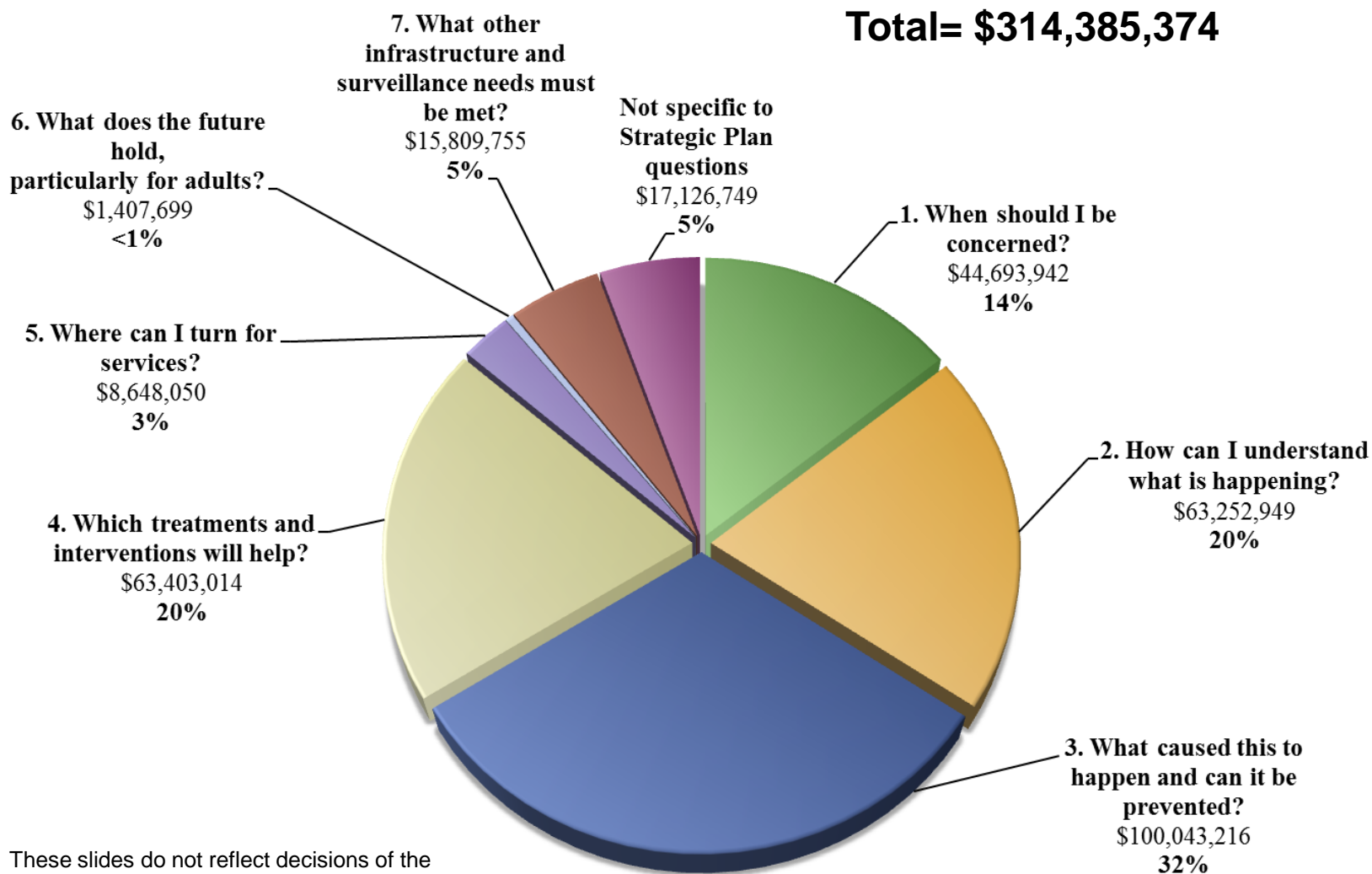


Impact of NIH-ARRA on Total ASD Research Funding



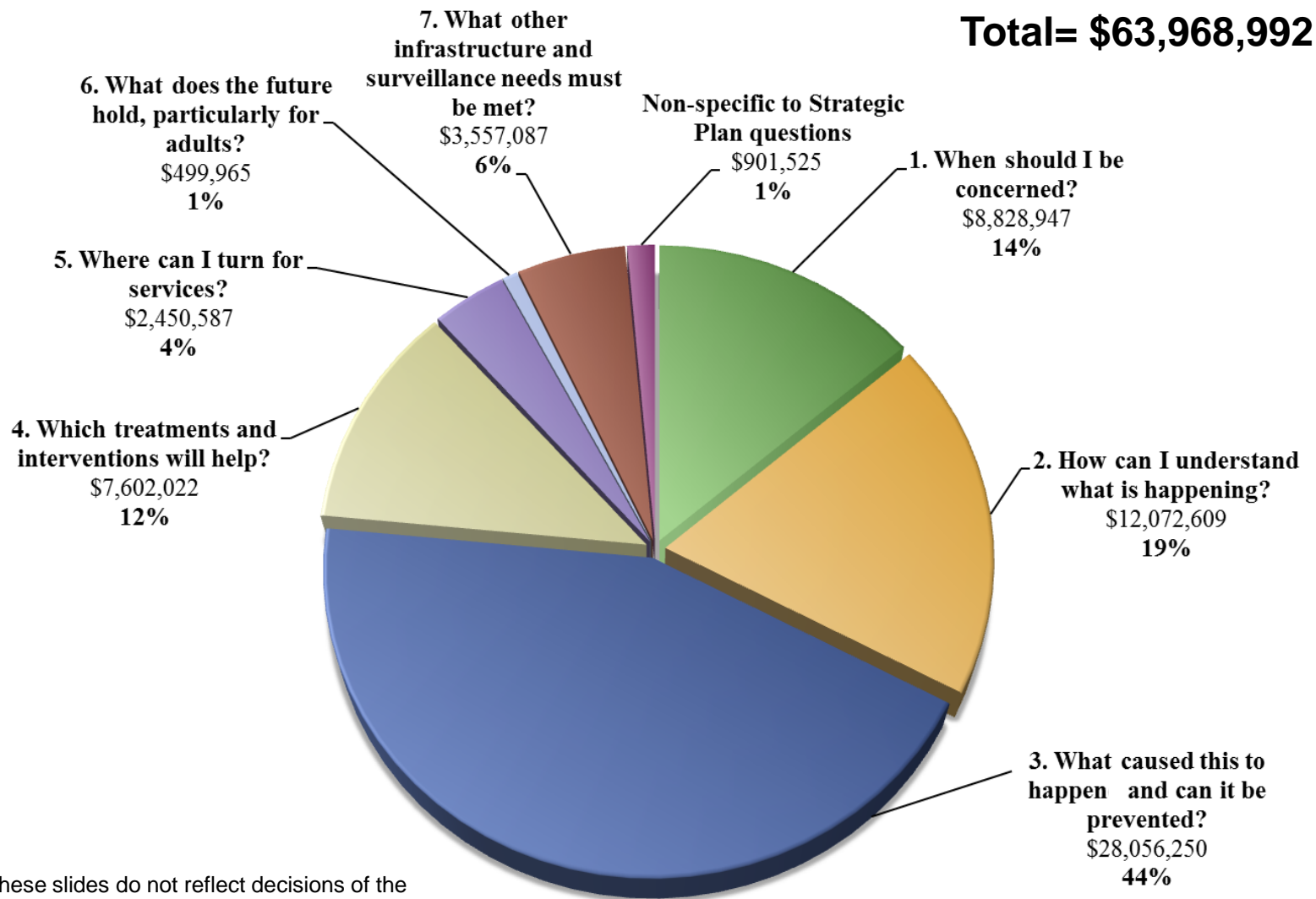
- \$64M in 2009 NIH-ARRA funds were used to support autism related research.
- NIH ARRA funding accounted for:
 - 20% of all 2009 ASD research funding (\$316M)
 - 33% of NIH funding (\$196M)
 - 27% of federal funding (\$239M)

2009 ASD Research Funding by Strategic Plan Question



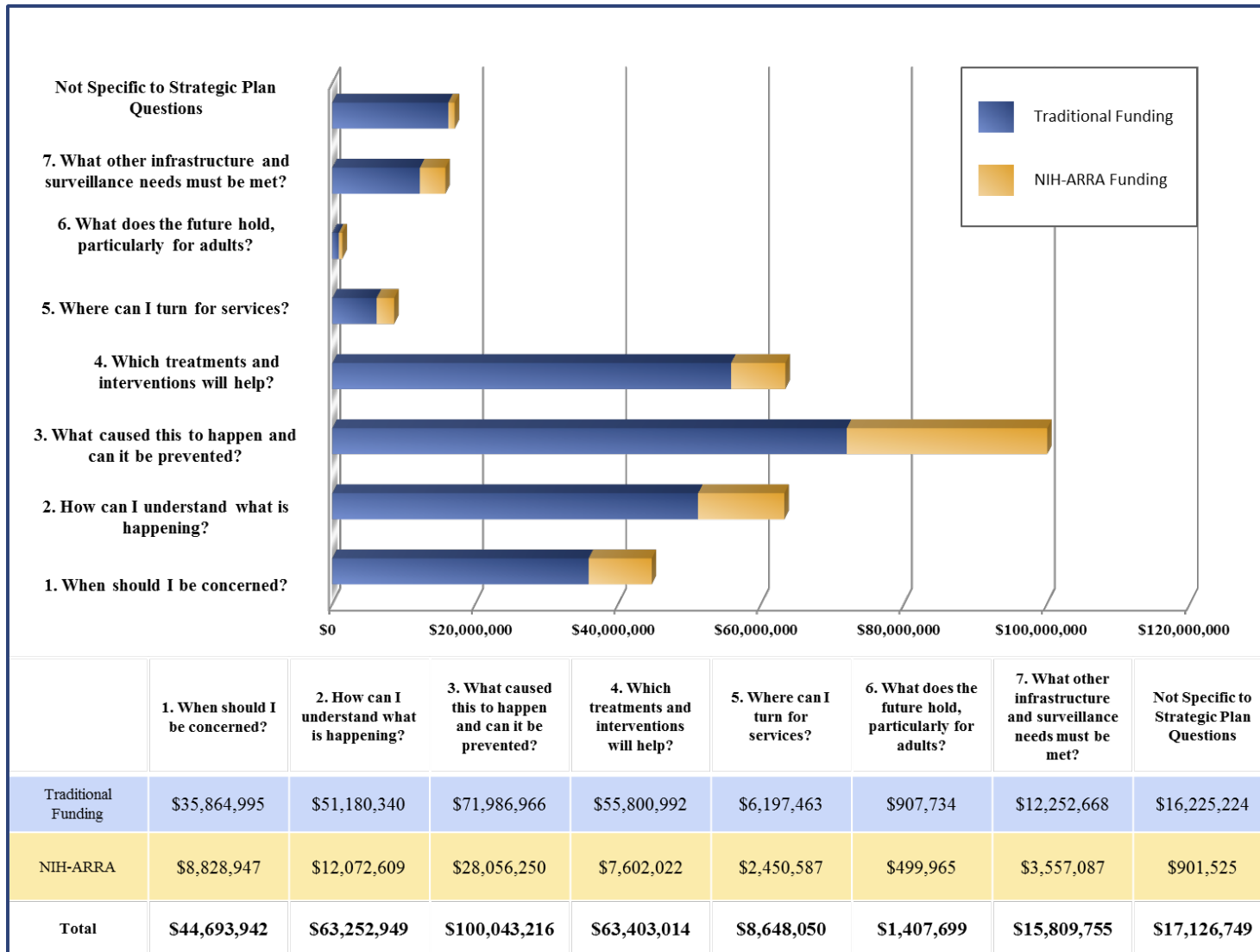
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2009 NIH-ARRA ASD Research Funding by Strategic Plan Question



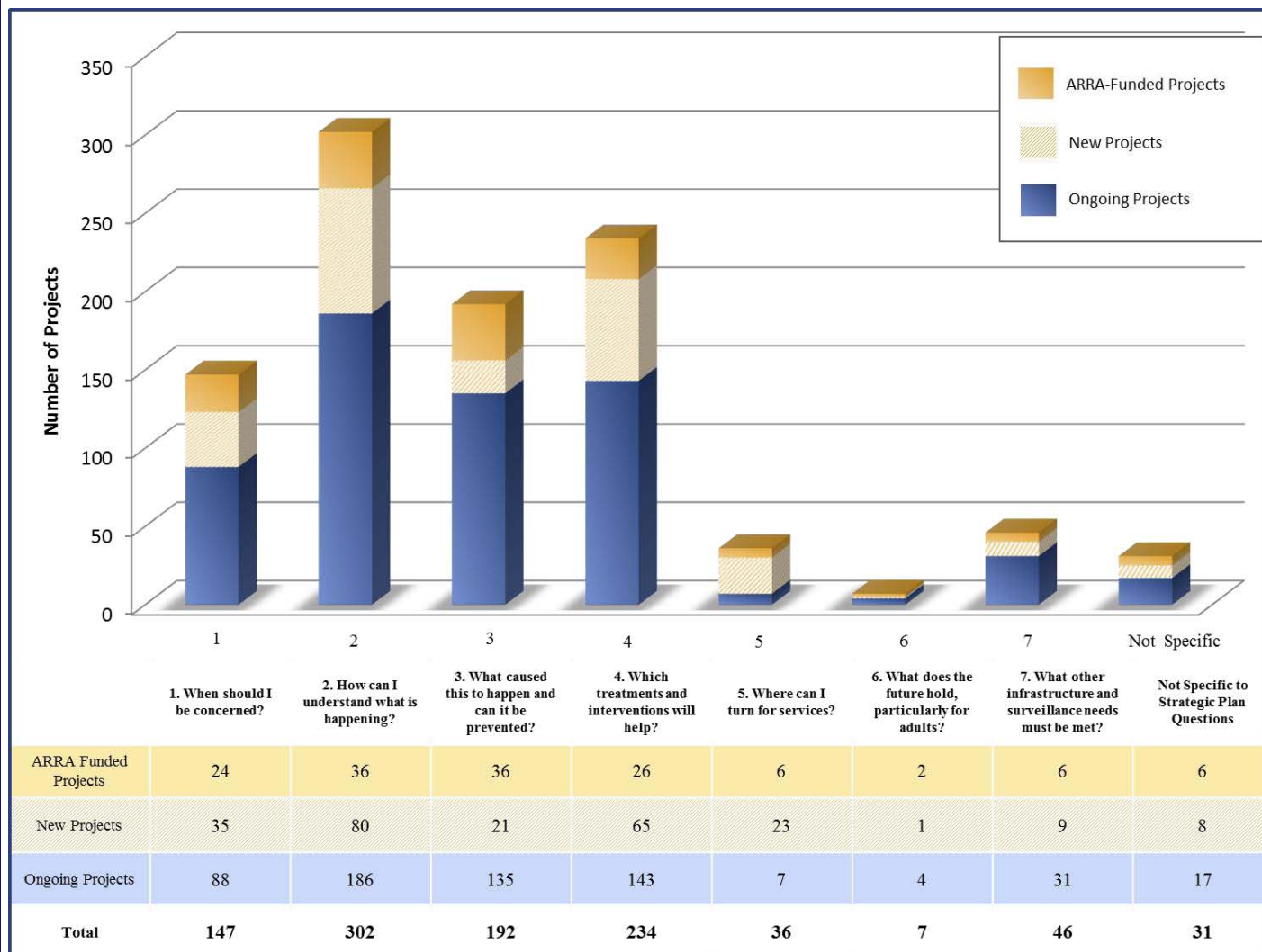
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Impact of 2009 NIH-ARRA Funding on ASD Research: Alignment with the Strategic Plan



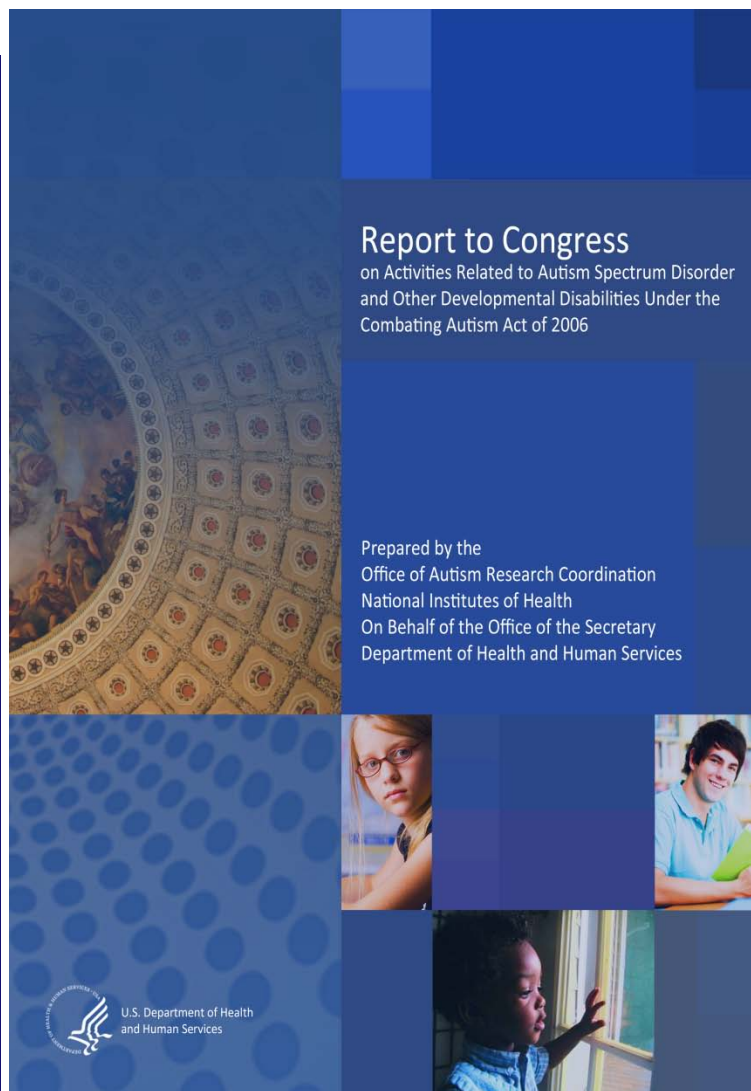
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New Investments in ASD Research in 2009



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HHS Secretary's Report to Congress on Activities Related to the Combating Autism Act of 2006



- Required by Public Law 109–416, the Combating Autism Act of 2006 (CAA)
- Describes Federal progress and expenditures made in autism spectrum disorder (ASD) research and services activities since the enactment of the CAA
- Information gathered from HHS agencies (ACF, AHRQ, CDC, CMS, HRSA, NIH, OD, and SAMHSA) and the Department of Education
- Includes the latest information on prevalence, average age for diagnosis and intervention, effectiveness and outcomes of interventions, innovative intervention strategies, and adult services and supports
- Describes activities and publications of the IACC

All of these publications can be
accessed on the IACC website:

<http://iacc.hhs.gov>