The Autism Research Landscape: The IACC, Research Funding and Data Sharing

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&

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IMFAR
INTERNATIONAL MEETING FOR AUTISM RESEARCH

IACC
INTERAGENCY AUTISM COORDINATING COMMITTEE

Combating Autism Act (CAA) and the Interagency Autism Coordinating Committee

- Goals of Combating Autism Act of 2006:
  - Accelerate the pace of scientific discovery
  - Enhance Federal coordination of autism efforts
- Established the Interagency Autism Coordinating Committee (IACC) as the coordinating body
  - Federal and public members
- Combating Autism Reauthorization Act (CARA)
  - Reauthorized the CAA on September 30, 2011

New IACC Committee

Federal

Thomas Insel (NIMH, NIH)
James Battey (NIDCD, NIH)
Linda Birnbaum (NIEHS, NIH)
Coleen Boyle (CDC)
Francis Collins (NIH)
Denise Dougherty (AHRQ)
Tiffany Farchione (FDA)
Alan Guttmacher (NICHD, NIH)
Laura Kavanagh (HRSA)
Donna Kimbark (DoD)
Walter Koroshetz (NINDS, NIH)
John O'Brien (CMS)
Alexa Posny (Dept of Ed)
Sharon Lewis (Administration for Community Living)

Public

Idil Abdull (Parent, Somali American Autism Foundation)
James Ball (JB Autism Consulting)
Anshu Batra (Parent & Developmental Pediatrician)
Noah Britton (Self advocate)
Sally Burton-Hoyle (Family member, Eastern Michigan University)
Matthew Carey (Parent)
Dennis Choi (Simons Foundation)
Jose Cordero (University of Puerto Rico)
Jan Crandy (Parent, Nevada State Autism Assistance Program)
Geraldine Dawson (Autism Speaks)
David Mandell (University of Pennsylvania)
Lyn Redwood (Parent, Coalition for SafeMinds)
Scott Michael Robertson (Self advocate, Autistic Self Advocacy Network)
John Elder Robison (Self advocate & Author)
Alison Tepper Singer (Parent, Autism Science Foundation)

Red text indicates new committee members and/or new agencies represented on the committee

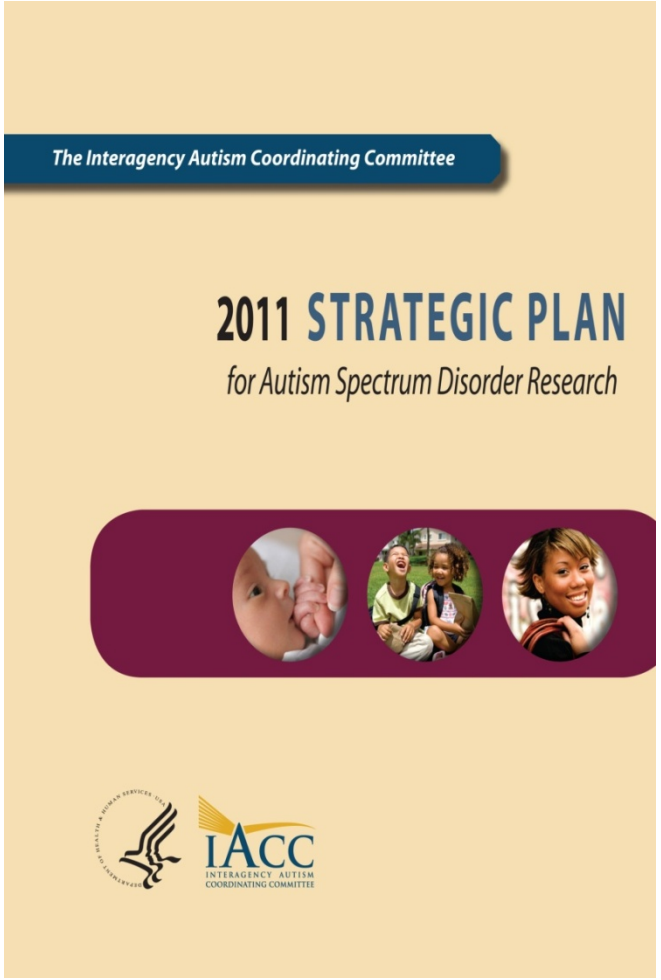
IACC Statutory Responsibilities

- Advise HHS' Secretary Sebelius
- Establish autism research priorities
  - **IACC Strategic Plan for ASD Research**
- Monitor Federal activities and analyze research trends
  - **IACC ASD Research Portfolio Analysis**
- Communicate advances in the field
  - **IACC Summary of Advances in ASD Research**

Next Meeting of the IACC

- **July 2012** – Stay tuned for details
- Will be announced on IACC website, IACC listserv and IACC Twitter
- All meetings open to public
- To receive notifications about IACC activities via e-mail or Twitter please send a message to: **IACCPublicInquiries@mail.nih.gov**

The IACC Strategic Plan



The IACC does not fund research, but encourages federal agencies and private organizations that fund ASD research to use the Strategic Plan in charting the course for new research

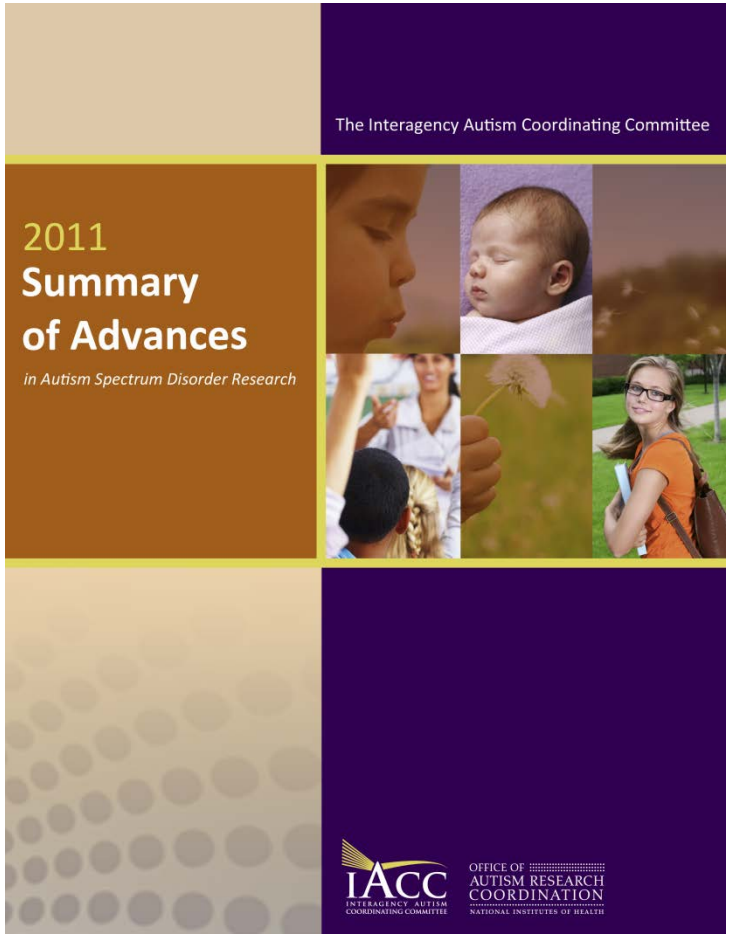
Purpose:

- Focus, coordinate, and accelerate high quality research
- Answer the urgent questions

Research Questions in the IACC Plan

1) **Diagnosis:** "When should I be concerned?"
2) **Underlying Biology:** "How can I understand what is happening?"
3) **Causes and Risk Factors:** "What caused this to happen and can this be prevented?"
4) **Treatments:** "Which treatments and interventions will help?"
5) **Services:** "Where can I turn for services?"
6) **Lifespan Issues:** "What does the future hold, particularly for adults?"
7) **Infrastructure, Data Sharing, & Surveillance:** "What other infrastructure and surveillance needs must be met?"

New Release:
2011 IACC Summary of Advances



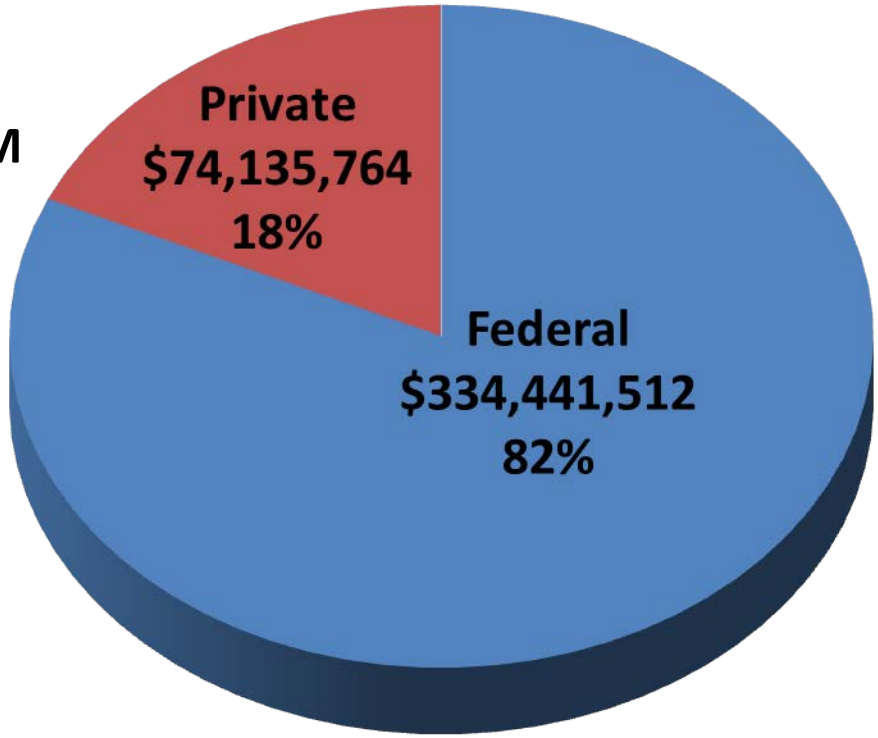
- 20 most significant advances in ASD biomedical and services research published in 2011
- Selected by the IACC
- New insights into ASD:
  - Prevalence
  - Biology
  - Risk factors
  - Interventions
  - Lifespan issues

Upcoming Release:
2010 IACC Portfolio Analysis

- Analyzes the ASD research portfolio across both Federal agencies and private organizations
- Monitors progress in fulfilling the objectives of the IACC Strategic Plan
  - The Plan contains78 research objectives - only 12 of 78 (15%) were not addressed by projects in 2010
- Highlights gaps and opportunities to guide future activities
- **Full report on 2010 data from all funders to be released Summer 2012**

2010 Federal and Private Autism Funding

- **Total funding = $408,577,276**
- **18 funders**
- **Overall Increase Since 2009 = $93M**



The 2010 Portfolio Analysis data reflect a larger proportion of overall funding from Federal sources, largely attributed to increased reporting from HRSA and the Department of Education, as well as several Federal funders of ASD research that were not captured in 2009 – NSF, EPA, ACF, AHRQ. Private funding remained similar to the 2009 level.

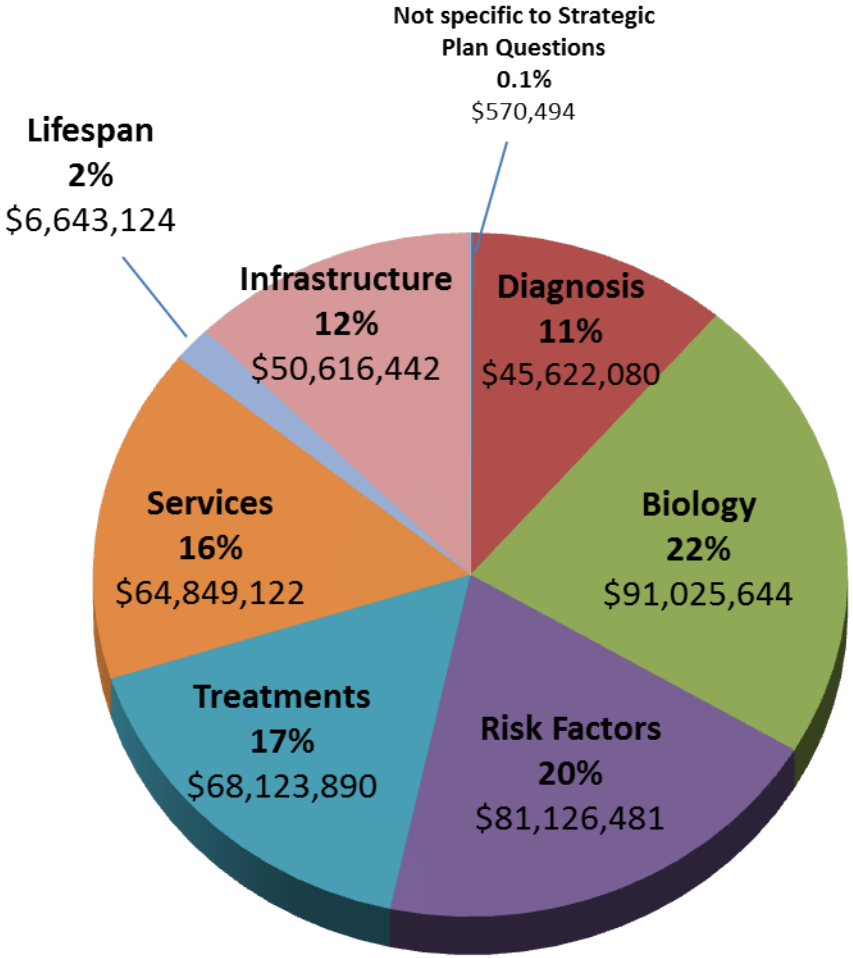
2010 Federal and Private Autism Funding

Funding Agency/Organization	Number of Projects	Total Funding
National Institutes of Health (NIH)	545	$217,143,701
The Simons Foundation (SF)	122	$53,729,921
Health Resources and Services Administration (HRSA)	82	$43,303,150
Department of Education (ED)	139	$30,432,564
Centers for Disease Control and Prevention (CDC)	30	$19,698,859
Autism Speaks (AS)	228	$18,476,890
National Science Foundation (NSF)	69	$12,222,206
Department of Defense (DoD)	58	$7,082,059
Administration for Children and Families (ACF)	1	$1,877,959
Agency for Healthcare Research and Quality (AHRQ)	4	$1,548,053
Center for Autism and Related Disorders (CARD)	31	$906,482
Environmental Protection Agency (EPA)	1	$756,802
Autism Research Institute (ARI)	15	$386,905
Centers for Medicare & Medicaid Services (CMS)	3	$376,159
Autism Science Foundation (ASF)	13	$245,000
Organization for Autism Research (OAR)	12	$191,590
Coalition for SafeMinds (SafeMinds)	8	$128,975
Southwest Autism Research & Resources Center (SARRC)	5	$70,000
GRAND TOTAL	**1367**	**$408,577,276**

Red text indicates private research funding organizations. Funding amounts for some agencies and organizations are estimates.

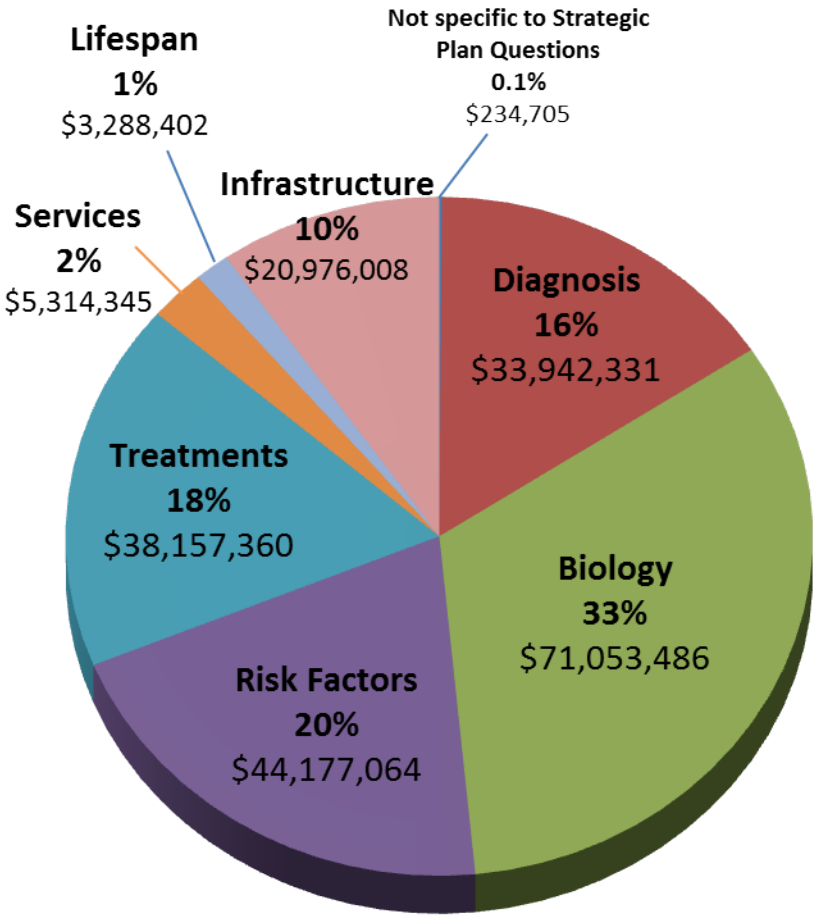
2010 Autism Funding by IACC Strategic Plan Question

All Funders



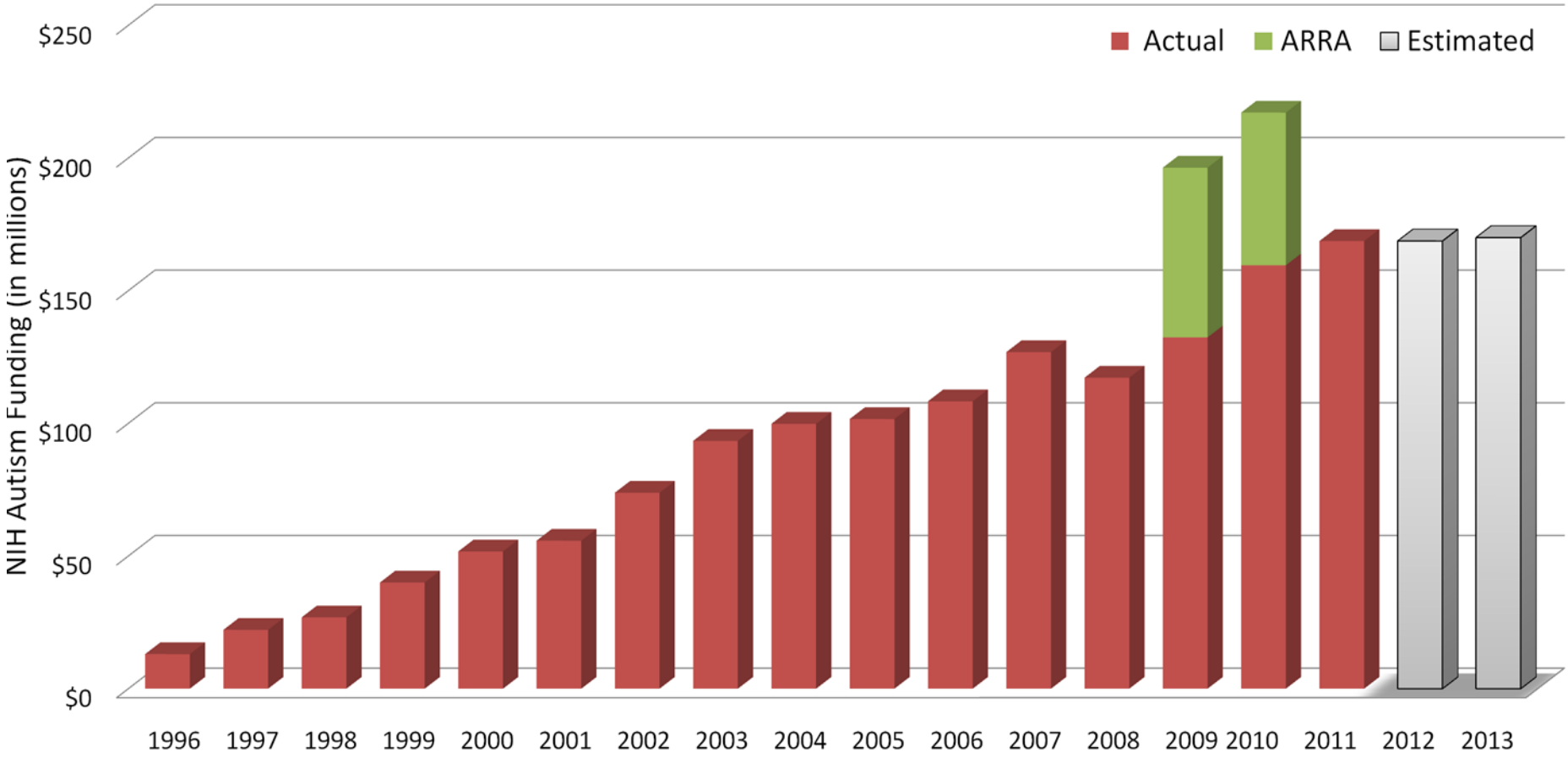
Total 2010 funding = $408,577,276

NIH Only – Including ARRA



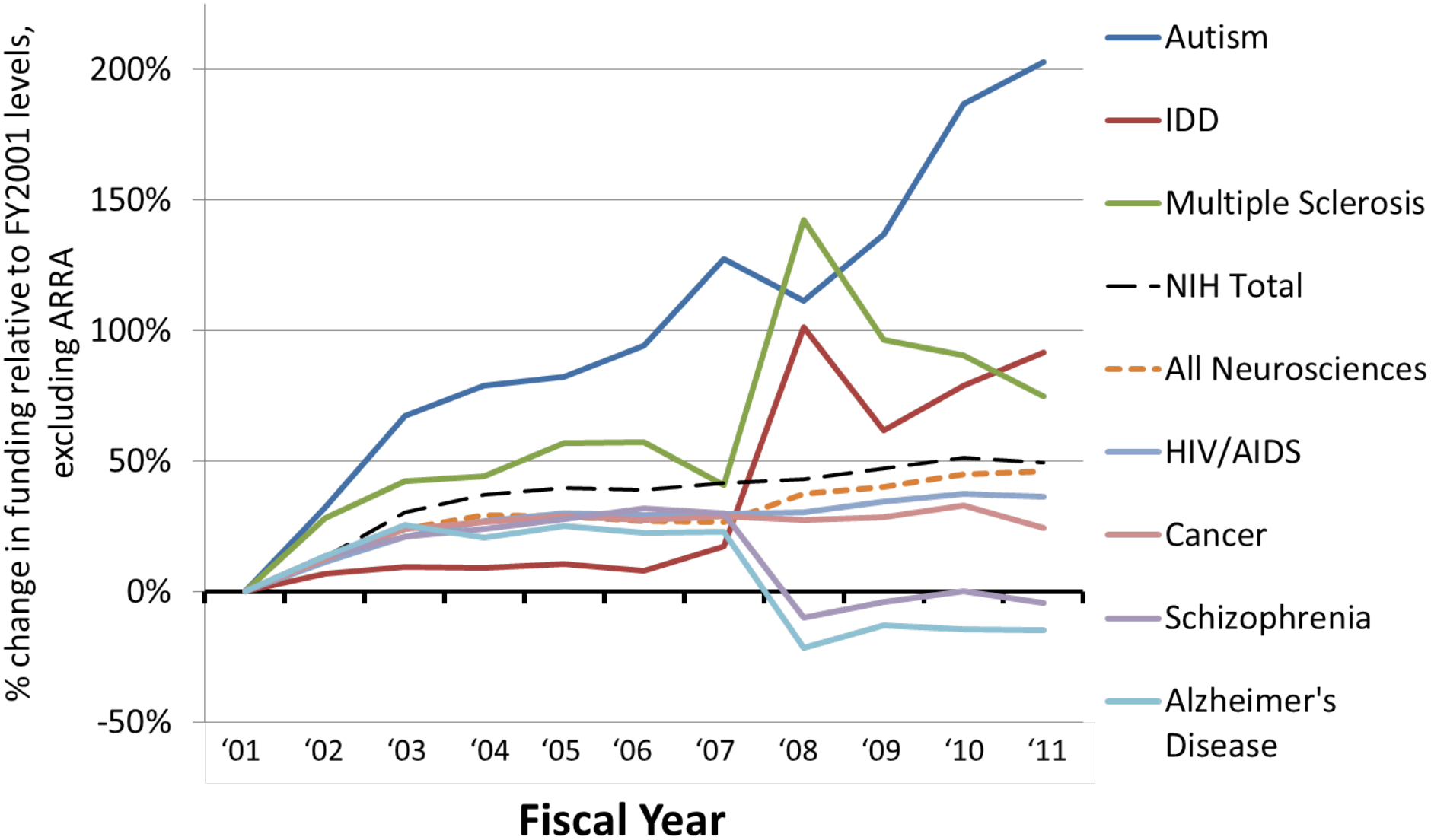
Total 2010 NIH funding = $217,143,701

NIH Autism Funding 1996-2013



NIH funding for autism research has tripled in the last decade (2001-2011).

NIH Autism Research Funding has Grown Rapidly (FY01-FY11)



NIH Autism Centers of Excellence (ACEs)

- The NIH ACE program encompasses centers and networks:
  - Centers foster collaboration between teams of specialists at the same facility.
  - Networks consist of researchers at many facilities in locations throughout the country.
- ACEs currently re-competing:

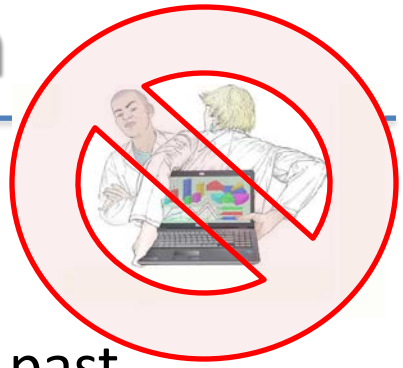
- Requirements of all ACE award recipients:
  - Strive to accomplish IACC Strategic Plan goals
  - Contribute their data to the National Database for Autism Research (NDAR)

National Database for Autism Research (NDAR)

- Housed at NIH, NDAR is a web-based tool that autism researchers can use to collect and share autism data
  - Contains data from over 25,000 subjects
  - Contains over 200,000 data elements
- ASD relevant data in NDAR:
  - Data types - phenotypic data, imaging and genomic/pedigree data related to human subjects
  - Data formats - text, numeric, image, time series, etc.
- NDAR has several tools for data definition, standardization and validation in order to help researchers to adopt community data standards across all projects and research institutions.

NDAR National Database for Autism Research
Serving the autism research community

We Need to Build a Culture of Data Sharing to Advance Autism Research



What needs to be done?

- Everyone needs to participate and share data
- Release data more quickly than you may have in the past

Why?

- Accelerates progress – reinterpretation, reuse and synthesis of data
- Facilitates collaboration, for increased statistical power and replication
- Required (NIH, NSF…) and responsible use of federal funds – Congress, taxpayers and advocates expect data sharing…in order to advance research and maximize research investments!
- Everyone benefits! (Especially affected individuals and families)

My Data or Data Mining?

Be responsible and do your part by sharing your data…

to protect the future of your funding and ensure continued Federal support for autism research.

Tom Insel
Director, NIMH

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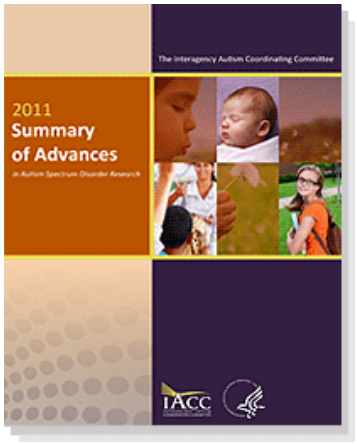

All IACC publications and more information about the IACC are available at:

www.iacc.hhs.gov

or at the IACC booth at IMFAR!

OFFICE OF AUTISM RESEARCH COORDINATION

NATIONAL INSTITUTES OF HEALTH

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