Meeting of the Interagency Autism Coordinating Committee

July 10, 2012

L'Enfant Plaza Hotel
408 L'Enfant Plaza, SW
Washington, DC 20024

Conference Call Access:

Phone: (888)455-5419

Access Code: 9404105

These slides do not reflect decisions of the IACC and are for discussion purposes only.

Meeting of the IACC

Morning Agenda

9:00AM **Call to Order and Opening Remarks**
Thomas Insel, M.D.
Director, NIMH and Chair, IACC

10:00 **The Honorable Kathleen Sebelius**
Secretary, US Department of Health and Human Services

10:30 **The Honorable Michael Doyle**
US House of Representatives
14th District of Pennsylvania

10:40 **The Honorable Christopher Smith**
US House of Representatives
4th District of New Jersey

Meeting of the IACC

IACC Introduction

Thomas R. Insel, M.D.
Director, National Institute of Mental Health
Acting Director, National Center for Advancing Translational Sciences
Chair, IACC
IACC Full Committee Meeting – July 10, 2012

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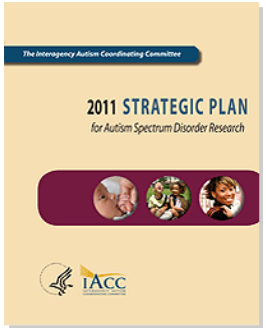
Responsibilities of the IACC

- Develop and update annually a summary of advances in ASD research
- Monitor Federal activities with respect to ASD
- Make recommendations to the HHS Secretary regarding research or public participation
- Develop and annually update and submit to Congress a strategic plan for ASD research
- Meet at least twice/year



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What the IACC does:

- Advises the HHS Secretary
- Coordinates federal and non-federal activities (science and services)
- Focuses and accelerates progress via Strategic Plan
- Serves as a public forum

What the IACC does NOT do:

- We do not fund research
- We do not set policy
- We do not have the authority to force agencies to fund specific projects or set specific policies

But, we can coordinate and focus efforts to accelerate progress by working together.

IACC Core Values

- Sense of urgency
- Scientific excellence
- Spirit of cooperation
- Consumer focus
- Partnerships in action
- Accountability (SMART objectives – specific, measurable, achievable, realistic, time-bound)

"finding common ground"

IACC Traditions

- Public comments (written and oral)
- Scientific updates (brief overviews)
- Policy updates and policy plans
- Member updates (round robin)
- Committee business (fulfilling our responsibilities) – IACC activities and subcommittee reports

IACC 2.0

- New federal and non-federal members
- Need for external scientific expertise
- Short time-line: September 30, 2014
- Increasing frustration: signs of progress, but increasing problems as well

Welcome

Let’s get to work!

Vision Statement

The Strategic Plan will accelerate and inspire research that will profoundly improve the health and well-being of every person on the autism spectrum across the lifespan. The Plan will set the standard for public-private coordination and community engagement.

IACC Strategic Plan Introduction 2011

Meeting of the IACC

10:50 **Kareem Dale, J.D., MBA**
Associate Director
White House Office of Public Engagement &
Special Assistant to the President for Disability Policy

11:00 **Michael Strautmanis, J.D.**
Deputy Assistant to the President and Counselor for Strategic Engagement to the Senior Advisor
Executive Office of the President

11:10 **Alexa Posny, Ph.D.**
Assistant Secretary of Special Education and Rehabilitative Services
US Department of Education

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Meeting of the IACC

11:10 **Francis Collins, M.D., Ph.D.**
Director
National Institutes of Health

12:00 PM **Lunch**

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Meeting of the IACC

Lunch Break

Meeting of the IACC

Afternoon Agenda

1:00 **Public Comments**

1:30 **ASD Science Update**
Thomas Insel, M.D.
Director, NIMH and Chair, IACC

1:45 **Administration for Community Living**
Henry Claypool
Principal Deputy Administrator, ACL

2:00 **Update on Seclusion and Restraint**
Larry Wexler, Ph.D.
Director, Research to Practice Division
Office of Special Education Programs
US Department of Education

Meeting of the IACC

Open Session for Public Comment

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MindSpec
Informatics for Neurodevelopmental Disorders

Autism Reading Room:

A New Science Outreach Portal

http://readingroom.mindspec.org

Our Team

President/Chief Scientific Officer

Sharmila Banerjee-Basu, Ph.D.

Director of Outreach

Catherine C. Swanwick, Ph.D.

Scientists

Ajay Kumar, M.S.
Eric C. Larsen, Ph.D.
Tim Wadkins, Ph.D.
Idan Menashe, Ph.D.
Wayne Pereanu, Ph.D.
Ishita Das, Ph.D.

Developers

Rainier Rodriguez
Wayne Pereanu, Ph.D.
Ravi Kollu, M.S.
Saumyendra N. Basu, M.S.

Writers

Caroly Shumway, Ph.D.
Lindsay Smith-Buckley, Ph.D.
Shana Spindler, Ph.D.

MindSpec
Informatics for Neurodevelopmental Disorders

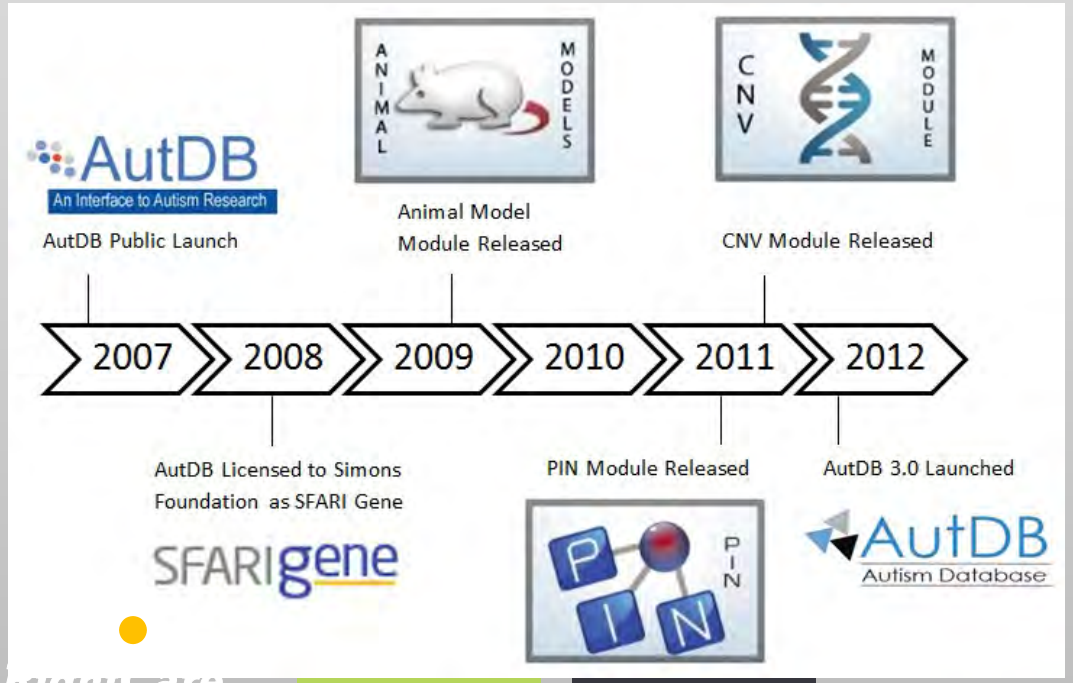
Goals

- Databases
- Research
- Outreach

AutDB: Autism Database

- Genetic database for autism
- Modular design based on systems biology
- First disease-driven database to include both rare and common variants
- Licensed to Simons Foundation as SFARI Gene

Timeline



MindSpec
Informatics for Neurodevelopmental Disorders

Goals

- Databases
- Research
- Outreach

RightCare
YOUR HEALTHCARE

Publications

- **Databases**
  - AutDB – **Nucleic Acids Research** (2009)
  - Animal Model – **BMC Medical Genomics** (2011)
  - Gene Scoring – under review, **Nature Genetics**
- **Analysis**
  - Predictive autism gene map – **PLoS One** (2011)
  - CNV analysis – under review
- **Reviews**
  - Genetic heterogeneity of autism – **Intech Book Chapter** (2011)
  - Genetic testing and autism – **Intech Book Chapter** (2012)

Citations

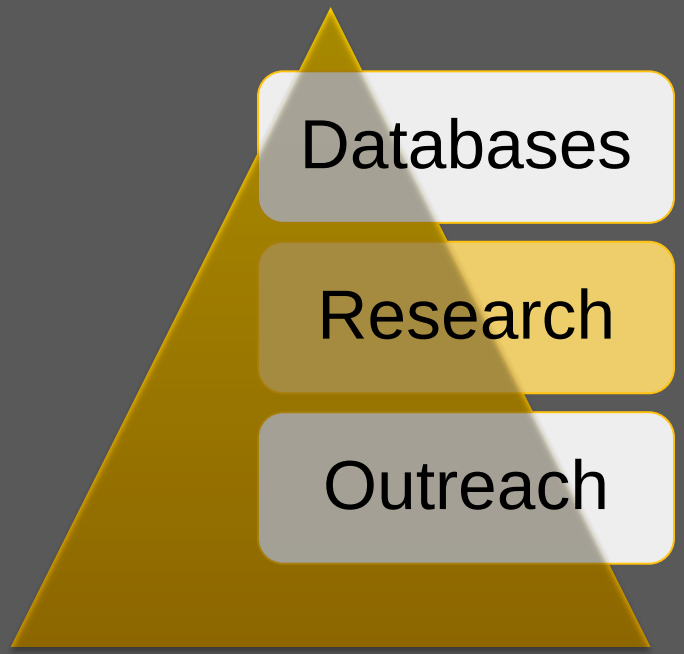
>25 peer-reviewed citations to AutDB since its original NAR publication in 2009

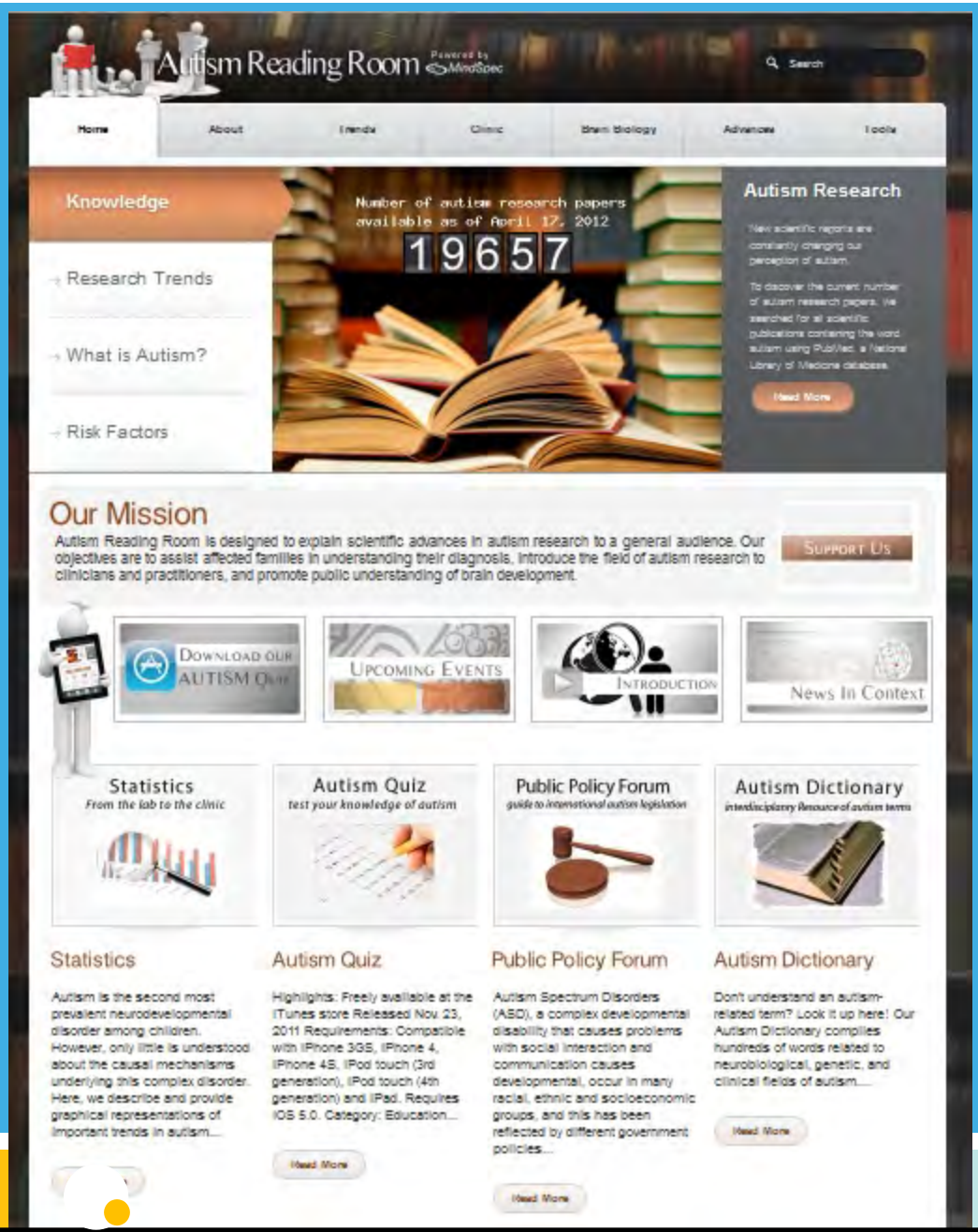
RightCare

MindSpec

Informatics for Neurodevelopmental Disorders

Goals





http://readingroom.mindspec.org

YOUR HEALTHCARE

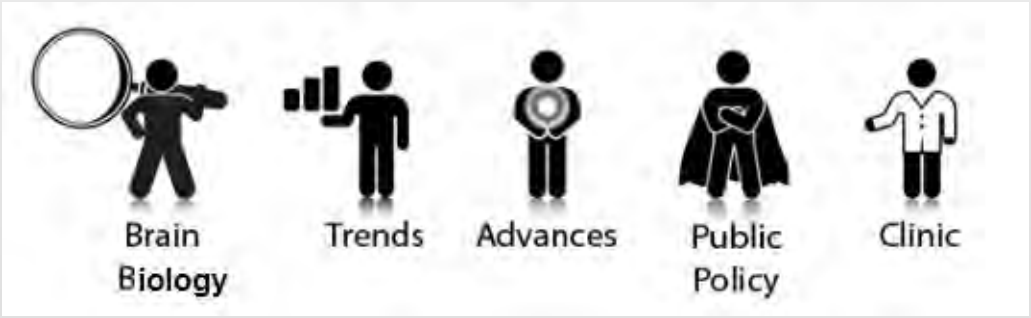
MindSpec

Informatics for Neurodevelopmental Disorders

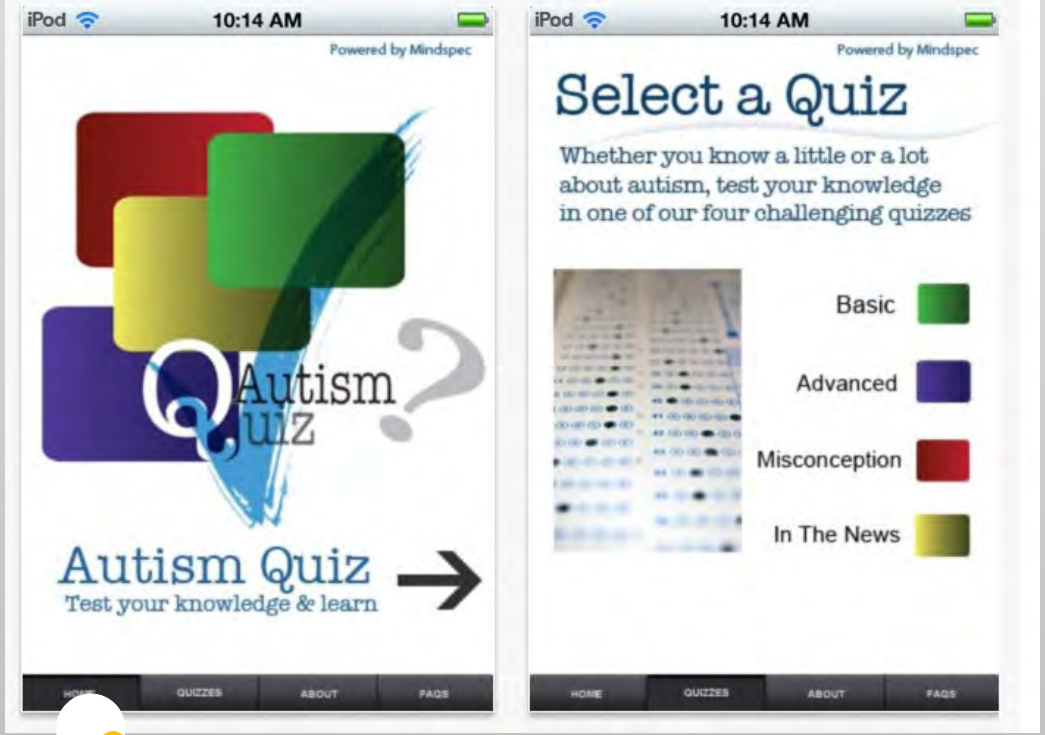
Goals

- Databases
- Research
- Outreach

Autism Reading Room Guides



Autism Quiz: free app on iTunes



http://readingroom.mindspec.org

MindSpec
Informatics for Neurodevelopmental Disorders

Goals

- Databases
- Research
- Outreach

Webinar Series:

Introduction: What is Autism Reading Room?

July 24, 26 (12:00 – 1:00 PM)
August 21, 23 (12:00 – 1:00 PM)

September – Prevalence

October – Brain Biology

November – Genetics

December – Environmental Factors

Registration : catherine@mindspec.org

MindSpec
Informatics for Neurodevelopmental Disorders

Goals

- Databases
- Research
- Outreach

Autism prevalence time trends, risk factors & prenatal ultrasound

A unifying hypothesis in four parts

By Caroline Rodgers

Temperature & Pregnancy

Unifying hypothesis

Thermal intrusions on the fetal environment of any kind increase the risk of autism

Prenatal ultrasound produces heat when the sound waves it generates are absorbed by tissue

The constantly expanding application of ultrasound to prenatal care is driving the autism epidemic

Fetal temperature regulation is critical to proper neurological development

Hot tubs – neural tube defects [1]

Fever during labor – cerebral palsy [2]

Maternal heat-related events that increase autism risk

- Fevers [1,3]
- Infections [4]
- Fever-producing viruses [5]
- Drugs that disrupt the thermoregulatory system [6,7]

PART 1 AUTISM PREVALENCE & PRENATAL ULTRASOUND TIME TRENDS

Two data sets under consideration:

- Centers for Disease Control (CDC) autism prevalence figures from ADDM Network, 2000-2008 [8]
- Prenatal ultrasound time trends between 1995-2006 [9]

To arrive at the year of gestation, prenatal ultrasound exposure is reckoned nine years prior to 8-year-old cohort groups

AUTISM PREVALENCE INCREASES

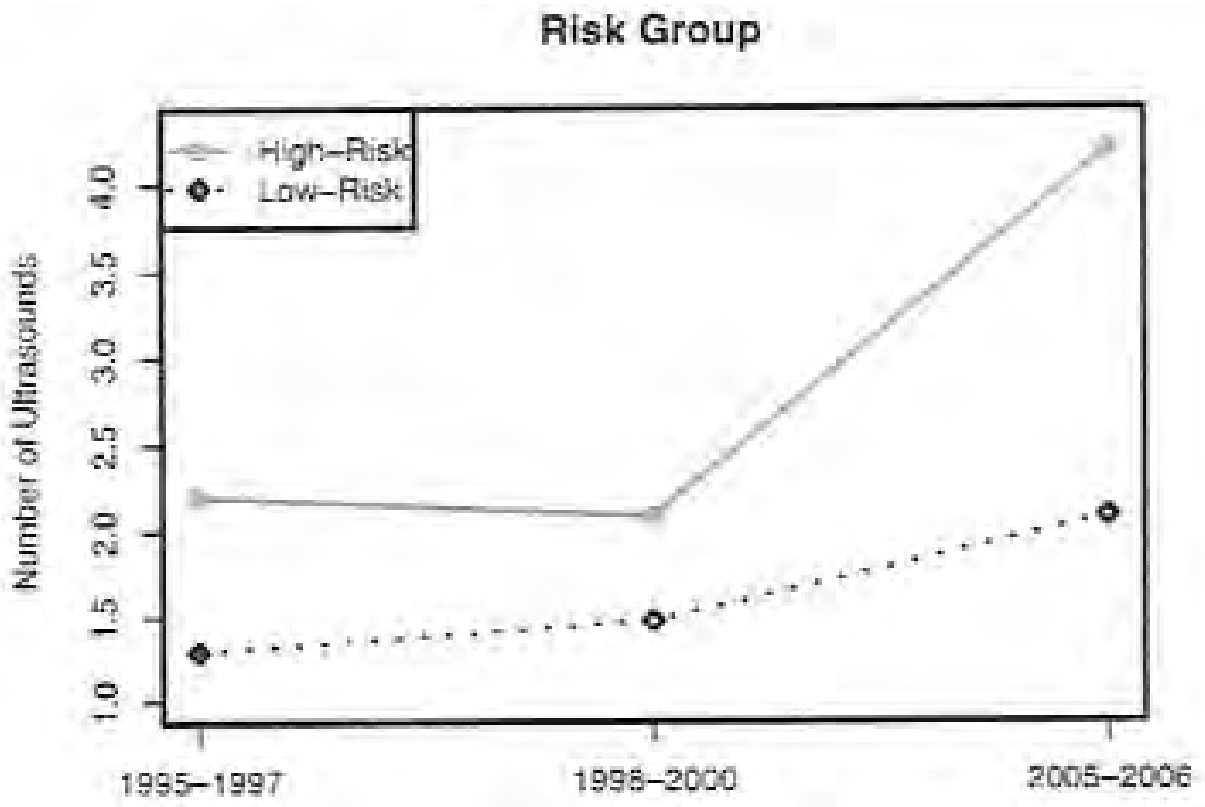
Identified Prevalence of Autism Spectrum Disorders
ADDM Network 2000-2008
Combining Data from All Sites

Surveillance Year	Birth Year	Number of ADDM Sites Reporting	Prevalence per 1,000 Children (Range)	This is about 1 in X children...
2000	1992	6	6.7 (4.5-9.9)	1 in 150
2002	1994	14	6.6 (3.3-10.6)	1 in 150
2004	1996	8	8.0 (4.6-9.8)	1 in 125
2006	1998	11	9.0 (4.2-12.1)	1 in 110
2008	2000	14	11.3 (4.8-21.2)	1 in 88

Up 78% between 2002-2008 [8]

http://www.cdc.gov/Features/CountingAutism

PRENATAL ULTRASOUND TIME TRENDS

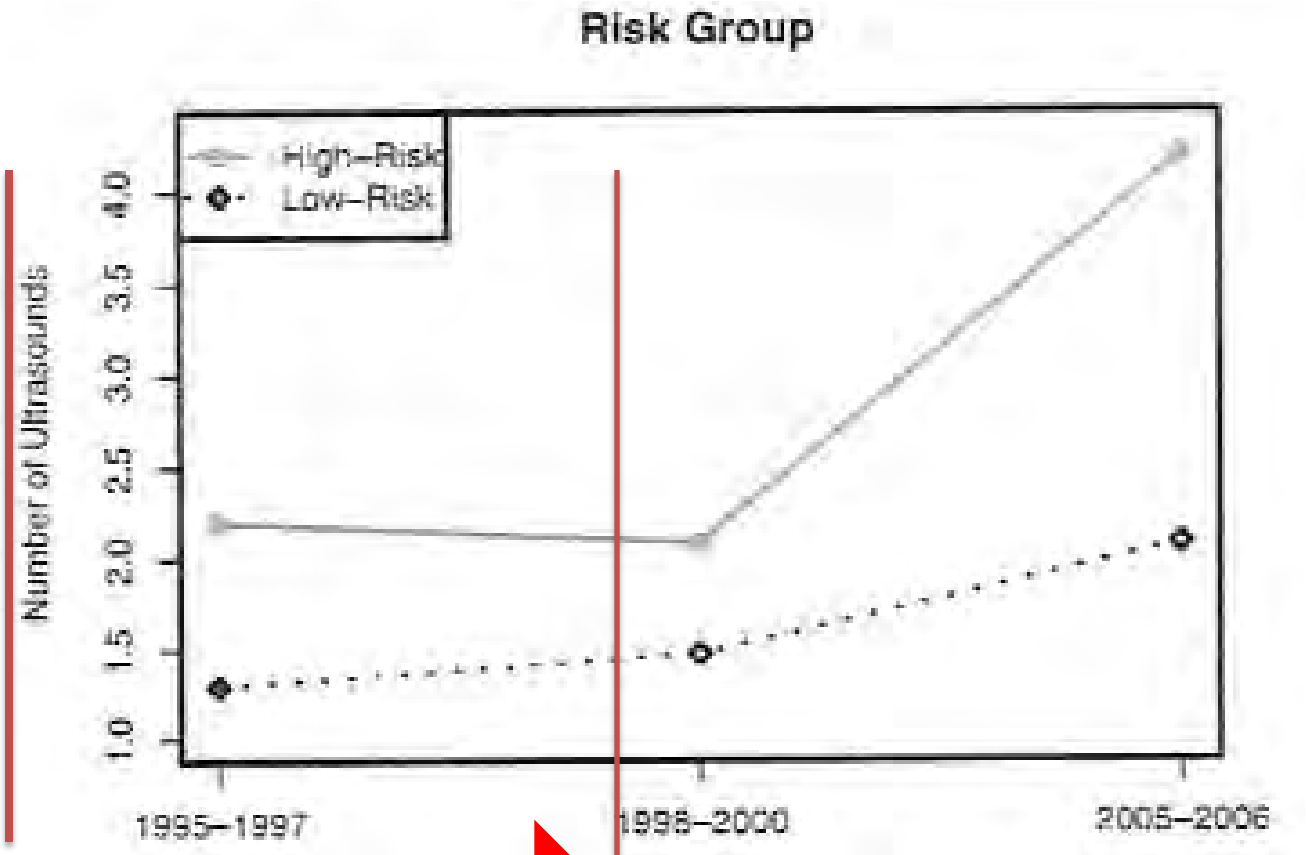


graph from : "Trends in prenatal ultrasound use in the United States, 1995 to 2006"

Average number of scans per pregnancy increased 80% over 10 years [9]

High risk pregnancies	From 2.2 scans to 4.4
Low risk pregnancies	From 1.3 scans to 2.1

PRENATAL ULTRASOUND TIME TRENDS

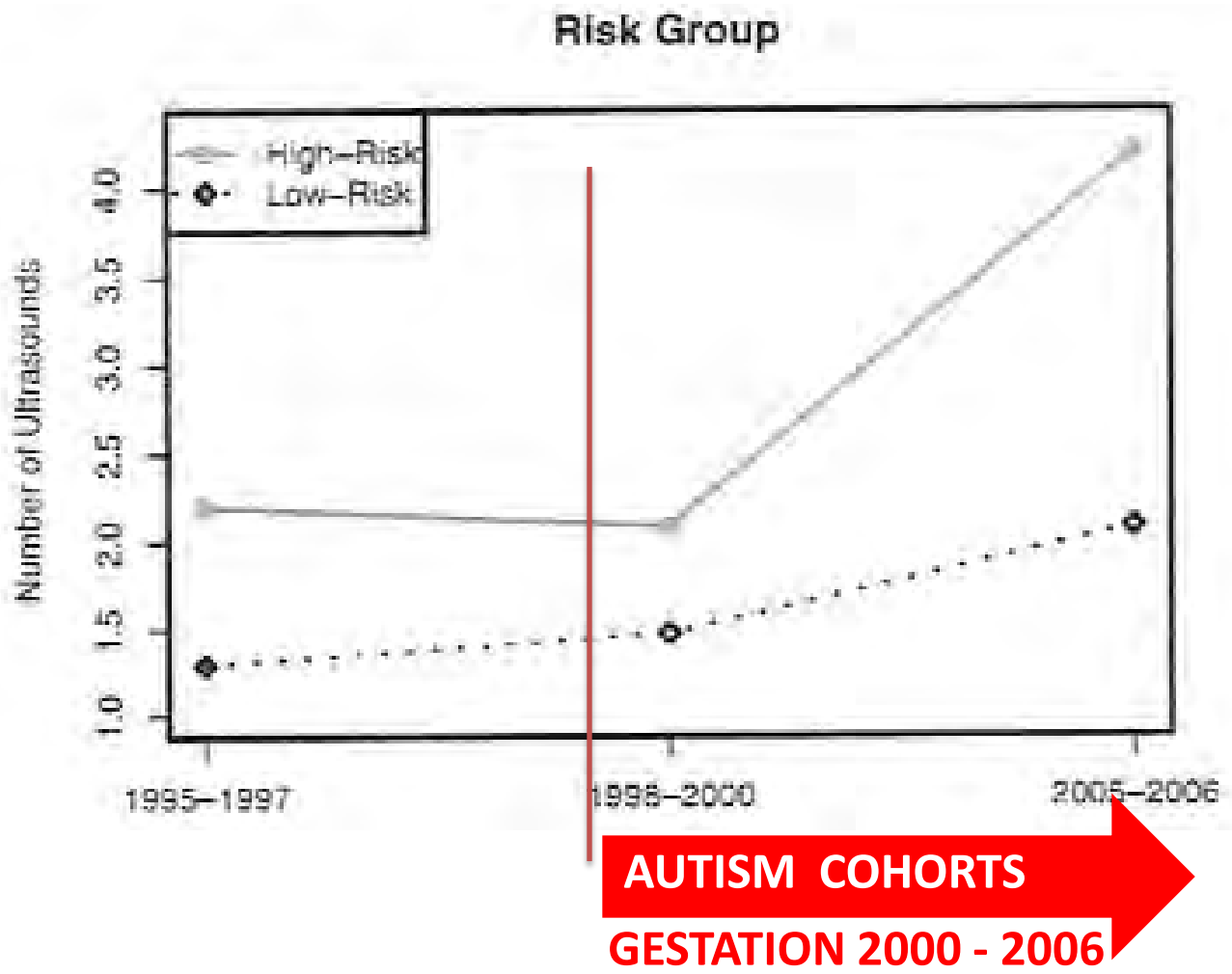


AUTISM COHORTS

GESTATION 1993 - 1999

Increase in number of prenatal ultrasound scans in low-risk & high-risk mothers [9]

PRENATAL ULTRASOUND TIME TRENDS



Effect of ultrasound increases beyond1999 will not be evident until data are available for 8-year-old cohorts from 2009 to 2015

Increase in % of women undergoing ultrasound

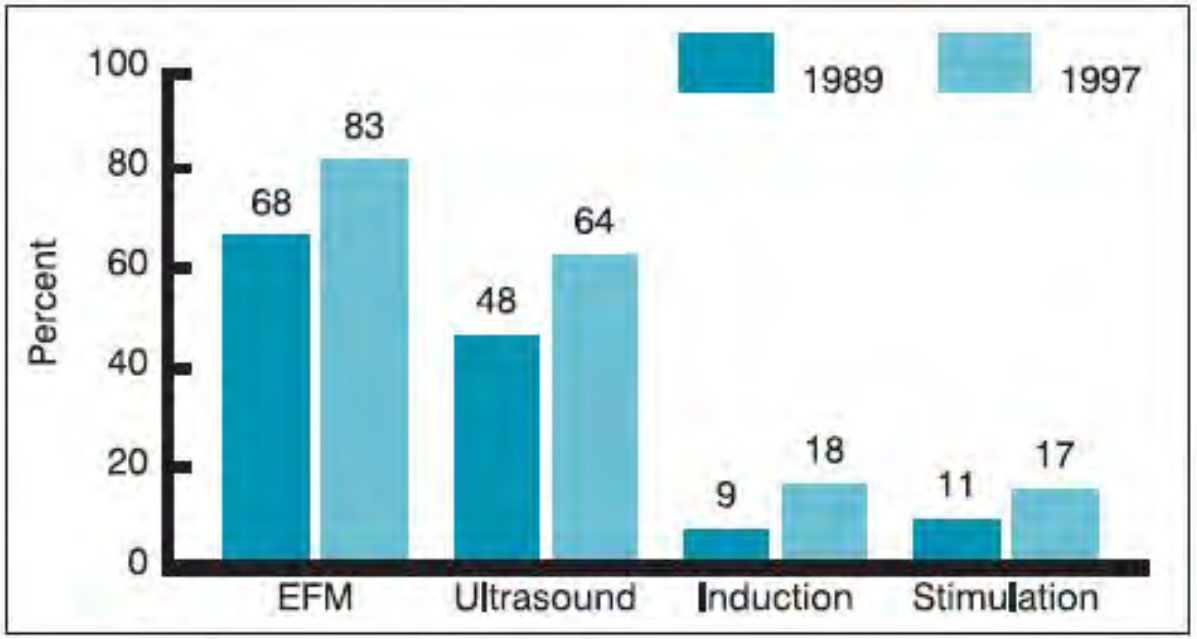


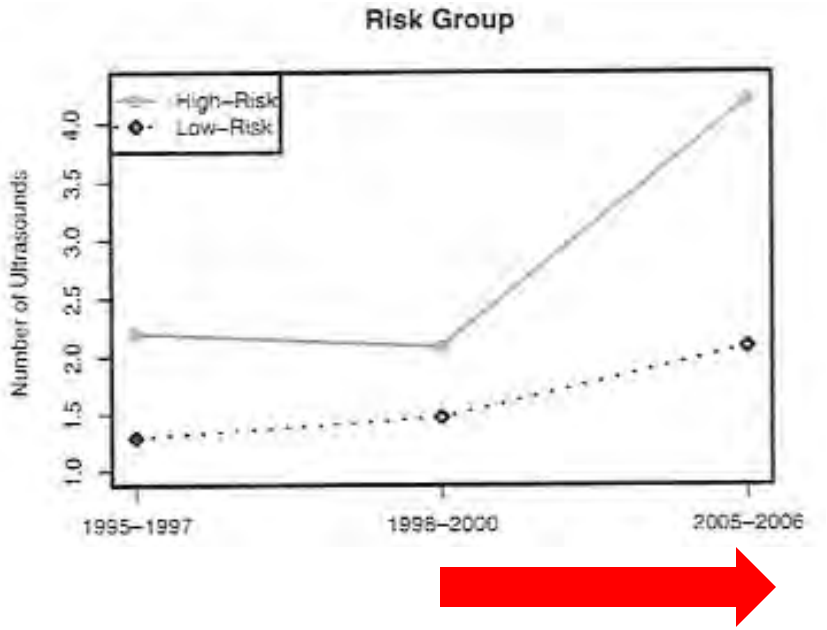
Figure 5. Percent of births that included electronic fetal monitoring (EFM), ultrasound, induction, or stimulation of labor: United States, 1989 and 1997

Chart from: Births: final data for 1997. Natl Vital Stat Rep

Increased from just under a half to a majority during the 1990s [10]

PART 1 Observation

If there is a correlation between prenatal ultrasound and autism, autism prevalence will increase much more sharply in the cohorts in gestation from 2000 through 2006



PART 2 AUTISM RISK FACTORS: MATERNAL OBESITY

- Childhood Autism Risk Factors from Genetics and Environment (CHARGE) Study found that obese mothers were 67% more likely to have a child diagnosed with autism than controls [11]
- In the U.S. about 1/3 women of childbearing age are obese

U.S.
Autism
1 in 88 [8]

U.S.
World
Highest
Adult
Obesity
30.6% [12]

South Korea Obesity Tied
For Last Place at 3.2% [12]

South
Korea
Autism
World's
Highest
1 in 38 [13]

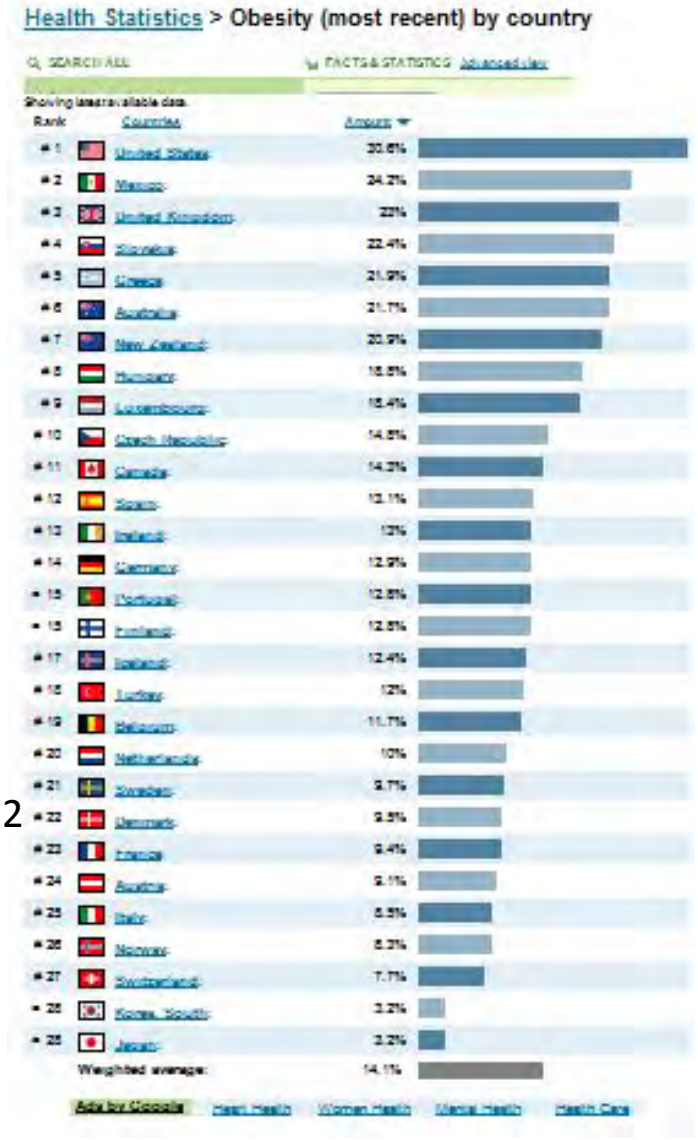
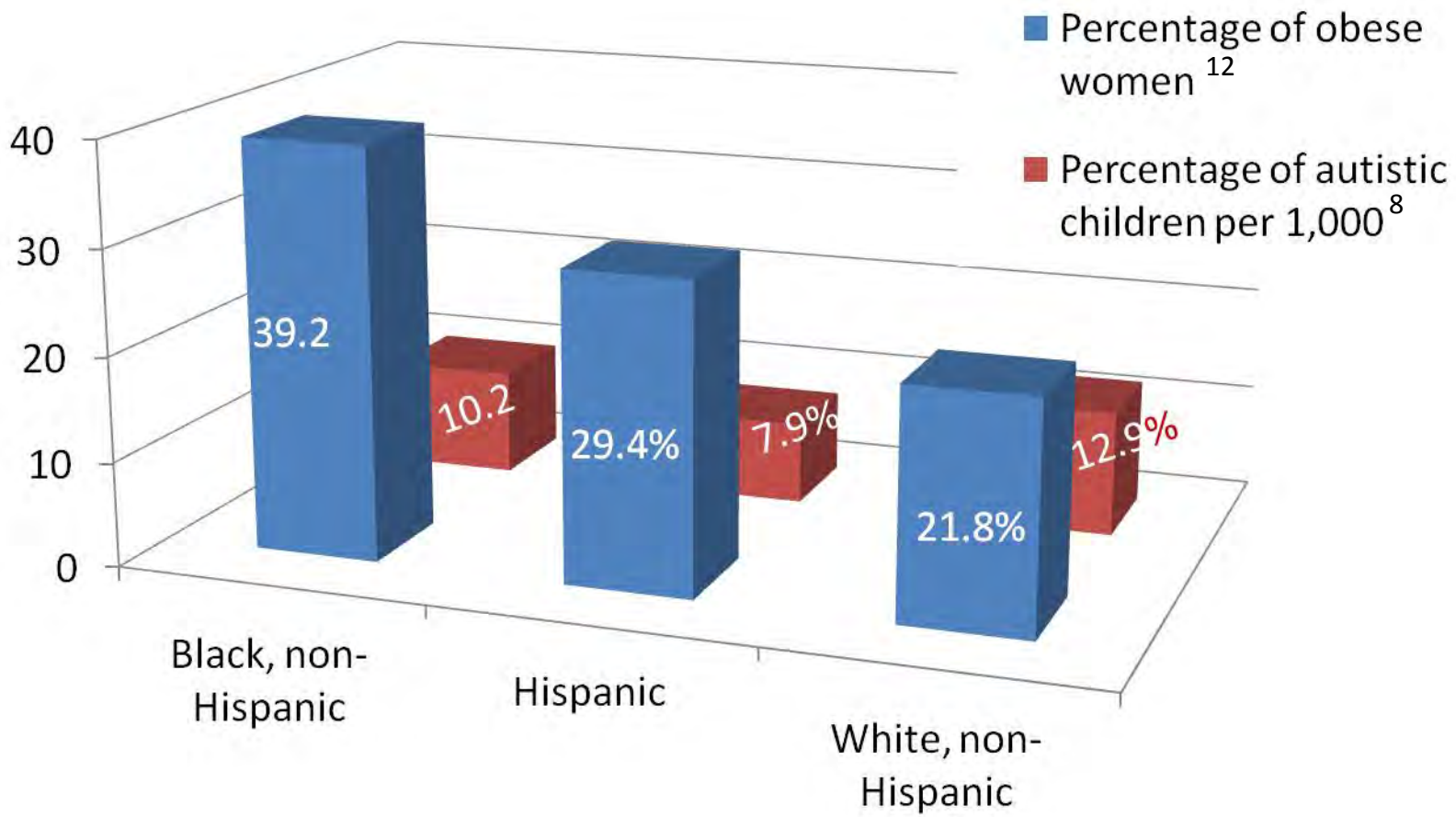


Chart from: http://www.nationmaster.com/graph/hea_obe-health-obesity

U.S. FEMALE ADULT OBESITY & AUTISM PREVALENCE BY ETHNIC GROUPS



Obesity data from "Differences in prevalence of obesity among black, white, and Hispanic adults – United States, 2006-2008." MMWR Morb Mortal Wkly Rep. 2009;58(27):740-4.

What could explain the U.S. obesity-autism association *and* South Korea's high autism rate

Types of prenatal ultrasound equipment

- Transabdominal transducer (standard)
  - Glides over belly
  - Transmits sound waves through abdominal wall
  - Produces image with frequencies in the range of 3-5 MHz [15]
  - Used primarily in second and third trimester
- Transvaginal probe
  - Inserted in vagina
  - Transducer is physically closer to embryo/fetus
  - Ultrasound beam is unobstructed by abdominal wall
  - Produces better resolution images with frequencies in the range of 5-10 MHz [15]
  - Used primarily in first trimester and with obese women

Fact & conjecture

- FACT: Pregnancies of obese mothers are classified as high risk and as such, subject to more scans [9, 16]
- FACT: Obese mothers are more likely to be examined with transvaginal ultrasound further into pregnancy [17, 18]
- CONJECTURE: South Korean women are more likely to be exposed to ultrasound scans, including transvaginal ultrasound, because:
  - FACT: Transvaginal ultrasound produces higher resolution images [17] and South Korea has positioned itself on the cutting edge of medical imaging technology [19]
  - FACT: Medical specialist, who are more likely to order tests, make up more than 80% of South Korea's practicing doctors [20]
  - FACT: About 90% of Korean medical services are provided by the private sector, which has been found to overuse medical technology [20]

PART 2

Observation

Unless the reason children in South Korea develop autism is completely different from why children in the CHARGE study develop autism, there must be a common denominator

PART 3

Autism risk factors: fever

- Maternal fevers double the risk of autism [3]
- Fever-lowering medication reduces or eliminates the risk [3]

Autism Dev Disord
DOI 10.1007/s10803-013-1540-x

ORIGINAL PAPER

s Maternal Influenza or Fever During Pregnancy Associated
with Autism or Developmental Delays? Results
rom the CHARGE (CHildhood Autism Risks from Genetics
nd Environment) Study

Jeremy Zerbo · Ana-Maria Iosif · Cheryl Walker ·
elly Ozonoff · Robin L. Hansen · Irva Hertz-Picciotto

Springer Science+Business Media, LLC 2012

bstract We analyzed data from case groups of 538
ildren with autism spectrum disorders (ASD) and 163 with

Introduction

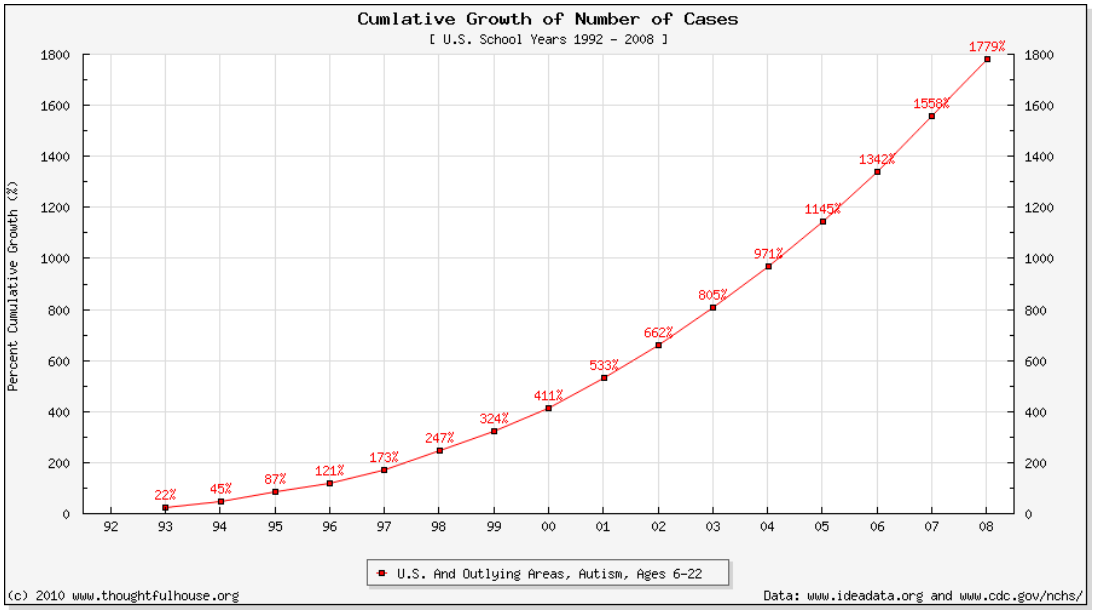
In conclusion, we did not find an association between maternal influenza infection during pregnancy and either ASD or developmental delay. However, mothers whose children had autism spectrum disorders at ages 2–5 years were more likely to report fever from any cause during pregnancy compared to those of similarly aged children with typical development. This was also true of mothers whose child had developmental delay. Our results additionally suggest that anti-fever medication used to control fever during pregnancy can reduce or eliminate the association we observed between maternal fever and autism.

PART 3 Observation

Fever studies explain the ‘odd uncle’ and other rare cases of autism that occurred naturally before the introduction of man-made thermal intrusions to the fetal environment

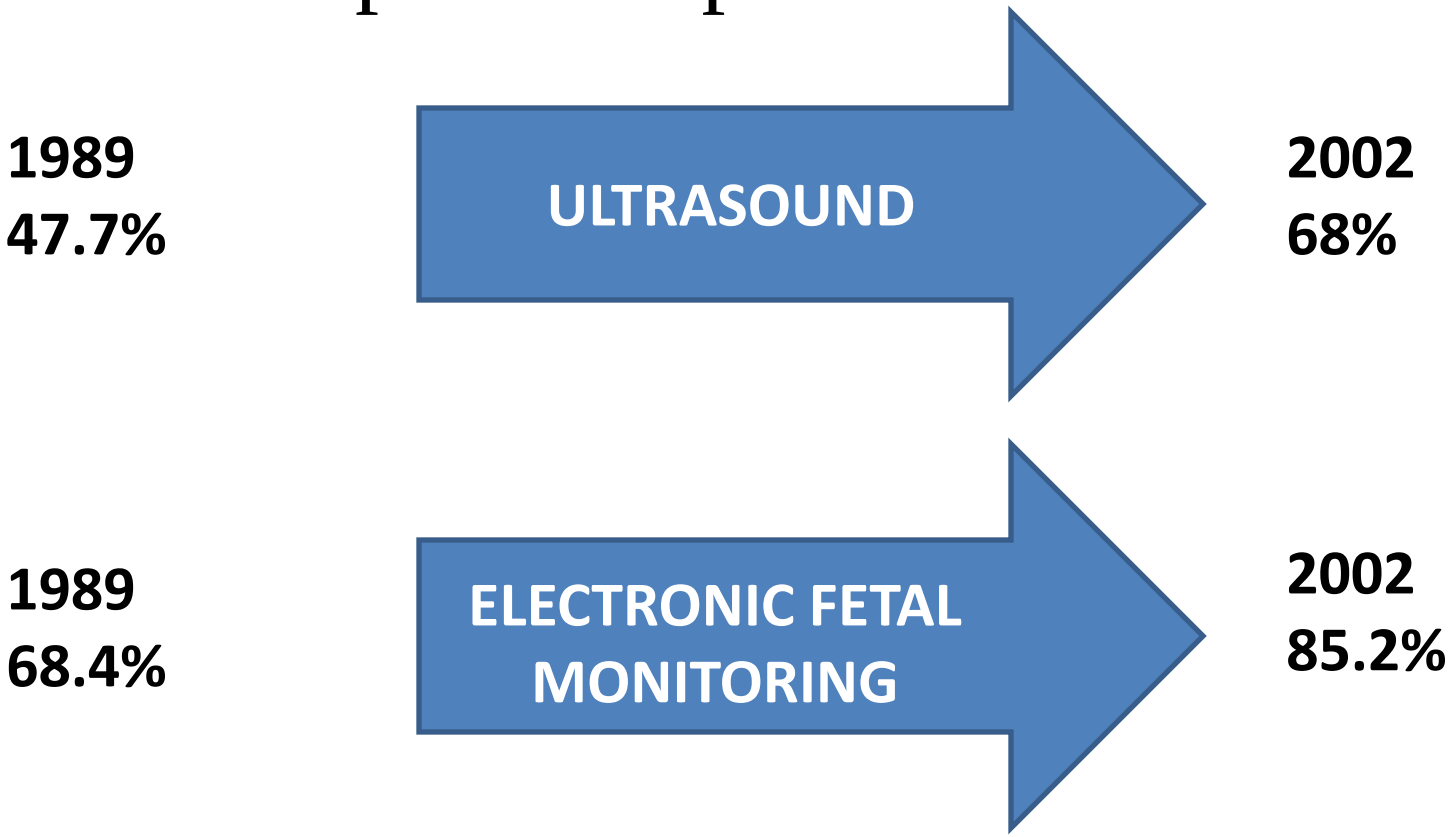
PART 4 The cause of autism is likely to be simple, not complex

The steady increase in autism argues against a complex etiology because the more factors involved in the disorder, the less likely it would progress in an even curve



Cumulative increase in autism in U.S. schools 1992-2008 [21]

Steady increase in percentage of U.S. women exposed to prenatal ultrasound



From1997 through 2002, the percentage of women exposed to ultrasound only increased four points over six years, from 64 to 68% [10, 22]

PART 4 Observation

The many maternal risk factors associated with autism such as fever, infection, viruses and certain drugs – or even pesticides and pollutants – have not increased steadily over time among the general population.

However, prenatal ultrasound use has increased steadily over time in the percentage of women exposed, the number of scans per pregnancy and the gestational window of exposure. During this period of increasingly great exposure, the technology has also changed, exposing fetuses to higher energy frequencies during the critical first trimester

How hypothesis fits unexplained autism facts

If thermal intrusions on the fetal environment are causing autism. . .

- . . . The de novo copy number variations associated with autism may be artifacts of heat-related genetic changes
- . . . It may explain regressive autism, since in utero thermal damage to heat-shock proteins or mitochondria could leave critical cells defenseless during the high fever that sometimes follows vaccinations
- . . . It may shed light on why some people with autism have a decrease in symptoms during fever episodes
- . . . Since male and female brains develop in different sequences, it might explain gender-related differences in autism prevalence

Re-defining autism

Changes in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) will not alter the fact that autism has become epidemic. The proof is in the urgent need for new services for children with autism who are aging out of the school system — which Autism Speaks calculates will number half a million over the next 10 years [23]

Conclusion

Thermal intrusions on the fetal environment of any kind can increase the risk of having a child with autism

Because the graph created by autism prevalence over time proceeds in an upward curve and does not have peaks and valleys, it is likely that a single thermal factor is driving the autism epidemic

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Meeting of the IACC

ASD Science Update

Thomas Insel, M.D.
Director, National Institute of Mental Health and Chair, IACC
IACC Full Committee Meeting – July 10, 2012

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When should I be concerned?

Predictive diagnostics: Biomarkers (MEG, DTI, EEG), Cognitive (eye gaze, video tasks), Screening (1 yr check up)

PEDIATRICS
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Six Developmental Trajectories Characterize Children With Autism

May 1, 2012

Christine Fountain, Alix S. Winter and Peter S. Bearman

THE AMERICAN JOURNAL OF PSYCHIATRY

Differences in White Matter Fiber Tract Development Present From 6 to 24 Months in Infants With Autism

Jason J. Wolff, Hongbin Gu, Guido Gerig, Jed T. Elison, Martin Styner, Sylvain Gouttard, Kelly N. Botteron, Stephen R. Dager, Geraldine Dawson, Annette M. Estes, Alan C. Evans, Heather C. Hazlett, Penelope Kostopoulos, Robert C. McKinstry, Sarah J. Paterson, Robert T. Schultz, Lonnie Zwaigenbaum, Joseph Piven, the IBIS Network

Am J Psychiatry 169:6, June 2012

BMC Medicine

A stable pattern of EEG spectral coherence distinguishes children with autism from neuro-typical controls - a large case control study

Frank H. Duffy and Heidelise Als

BMC Medicine 2012, 10:64

How can I understand what is happening?

Defining the problem: Synaptic pathology, Circuit disorder, Whole body issues (immune, GI, etc)

PNAS

Brain enlargement is associated with regression in preschool-age boys with autism spectrum disorders

Christine Wu Nordahl[a], Nicholas Lange[b], Deana D. Li[a], Lou Ann Barnett[a], Aaron Lee[a], Michael H. Buonocore[c], Tony J. Simon[a], Sally Rogers[a], Sally Ozonoff[a], and David G. Amaral[a,1]

PNAS | December 13, 2011 | vol. 108 | no. 50 |

PLoS one

Developmental Trajectories of Resting EEG Power: An Endophenotype of Autism Spectrum Disorder

Adrienne L. Tierney, Laurel Gabard-Durnam, Vanessa Vogel-Farley, Helen Tager-Flusberg, Charles A. Nelson

June 2012 | Volume 7 | Issue 6 | e39127

nature

Mutations causing syndromic autism define an axis of synaptic pathophysiology

Benjamin D. Auerbach, Emily K. Osterweil & Mark F. Bear

Nature. 2011 Nov 23;480(7375):63-8.

What caused this to happen and can it be prevented?

Genomic risk factors: New candidates, de novo mutations, rare events

PNAS

MAY 22, 2012

A common X-linked inborn error of carnitine biosynthesis may be a risk factor for nondysmorphic autism

Patrícia B. S. Celestino-Soper[a,1], Sara Violante[b,c,1], Emily L. Crawford[d], Rui Luo[e], Anath C. Lionel[f], Elsa Delaby[g], Guiqing Cai[h], Bekim Sadikovic[a], Kwanghyuk Lee[a], Charlene Lo[a], Kun Gao[e], Richard E. Person[a], Timothy J. Moss[a], Jennifer R. German[a], Ni Huang[i], Marwan Shinawi[a,j,2], Diane Treadwell-Deering[j,k], Peter Szatmari[l], Wendy Roberts[m], Bridget Fernandez[n], Richard J. Schroer[o], Roger E. Stevenson[o], Joseph D. Buxbaum[h], Catalina Betancur[g], Stephen W. Scherer[f,m], Stephan J. Sanders[p], Daniel H. Geschwind[e], James S. Sutcliffe[d], Matthew E. Hurles[i], Ronald J. A. Wanders[b], Chad A. Shaw[a], Suzanne M. Leal[a], Edwin H. Cook, Jr.[q], Robin P. Goin-Kochel[a,j,r], Frédéric M. Vaz[b,1], and Arthur L. Beaudet[a,j,r,1,3]

April 5, 2012

De novo mutations revealed by whole-exome sequencing are strongly associated with autism

Sanders, et al.

Sporadic autism exomes reveal a highly interconnected protein network of *de novo* mutations

O'Roak, et

Patterns and rates of exonic *de novo* mutations in autism spectrum disorders

Neale, et al.

What caused this to happen and can it be prevented?

Environmental risk factors: Results from CHARGE study

Is Maternal Influenza or Fever During Pregnancy Associated with Autism or Developmental Delays? Results from the CHARGE (CHildhood Autism Risks from Genetics and Environment) Study

Ousseny Zerbo • Ana-Maria Iosif • Cheryl Walker • Sally Ozonoff • Robin L. Hansen • Irva Hertz-Picciotto

Journal of Autism and Developmental Disorders
May 2012 [epub]

PEDIATRICS
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

April 9, 2012 [epub]

Maternal Metabolic Conditions and Risk for Autism and Other Neurodevelopmental Disorders

Paula Krakowiak, Cheryl K. Walker, Andrew A. Bremer, Alice S. Baker, Sally Ozonoff, Robin L. Hansen and Irva Hertz-Picciotto

Maternal periconceptional folic acid intake and risk of autism spectrum disorders and developmental delay in the CHARGE (CHildhood Autism Risks from Genetics and Environment) case-control study[1–3]

Rebecca J Schmidt, Daniel J Tancredi, Sally Ozonoff, Robin L Hansen, Jaana Hartiala, Hooman Allayee, Linda C Schmidt, Flora Tassone, and Irva Hertz-Picciotto

American Journal of Clinical Nutrition, July 2012

Which treatments and interventions will help?

New initiatives in medication development:
biomarker driven trials, public-private partnerships, leveraging on results w FraX and Rett

FNIH Biomarkers Consortium
- Autism Speaks, Simons Foundation, FDA, NIH, 5 companies

FAST Fail Trials in Autism Spectrum Disorders (FAST-AS) Initiative
- An NIMH initiative to implement rapid Proof of Clinical Mechanism (POCM) and Proof of Concept (POC) trials in order to quickly test and analyze novel interventions

Autism Treatment Network (ATN)
- Autism Speaks, HRSA, NIMH developing best practices, RCTs, biobank

Which treatments and interventions will help?

New findings w behavioral treatments:
Longer term effects, generalizability, pre-emptive Rx

Making the connection: randomized controlled trial of social skills at school for children with autism spectrum disorders

Apr 2012

Connie Kasari,[1] Erin Rotheram-Fuller,[2] Jill Locke,[3] and Amanda Gulsrud[1]

Longitudinal Follow-Up of Children With Autism Receiving Targeted Interventions on Joint Attention and Play

Connie Kasari, Ph.D., Amanda Gulsrud, Ph.D., Stephanny Freeman, Ph.D., Tanya Paparella, Ph.D., Gerhard Hellemann, Ph.D.

Journal of the American Academy of Child & Adolescent Psychiatry
VOLUME 51 NUMBER 5 MAY 2012

ORIGINAL PAPER

Pivotal Response Treatment for Infants At-Risk for Autism Spectrum Disorders: A Pilot Study

May, 2012

Amanda Mossman Steiner, Grace W. Gengoux, Ami Klin and Katarzyna Chawarska

Th

Where can I turn for services?

Economic and health issues: Effects on caregivers, costs of medical care

PEDIATRICS
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

March 19, 2012 [epub]

Implications of Childhood Autism for Parental Employment and Earnings

Zuleyha Cidav, Steven C. Marcus and David S. Mandell

Research in Developmental Disabilities

Volume 33, Issue 2, March-April 2012, pages 467-476

Concurrent medical conditions and health care use and needs among children with learning and behavioral developmental disabilities, National Health Interview Survey, 2006–2010

Laura A. Schieve, Vanessa Gonzalez, Sheree L. Boulet, Susanna N. Visser, Catherine E. Rice, Kim Van Naarden Braun, Coleen A. Boyle

Service and Wider Societal Costs of Very Young Children with Autism in the UK

Barbara Barrett, Sarah Byford, Jessica Sharac, Kristelle Hudry, Kathy Leadbitter, Kathryn Temple, Catherine Aldred, Vicky Slonims, Jonathan Green and PACT Consortium

Journal of Autism and Developmental Disorders, 2012, Vol. 42 No. 5, pgs. 797-804

What does the future hold, particularly for adults?

Estimating the Prevalence of Autism Spectrum Conditions in Adults:

Extending the 2007 Adult Psychiatric Morbidity Survey

NHS The Information Centre for health and social care

Jan. 31, 2012

Brugha T, Cooper SA, McManus S, Purdon S, Smith J, Scott FJ, Spiers N, Tyrer F

Journal of the AMERICAN GERIATRICS SOCIETY

Autism Spectrum Disorders in Older Adults: Toward Defining a Research Agenda

Joseph Piven and Peter Rabins, on behalf of the Autism-in-Older Adults Working Group
November 2011

Postsecondary Education and Employment Among Youth With an Autism Spectrum Disorder

PEDIATRICS *May 14, 2012 [epub]*

Paul T. Shattuck, Sarah Carter Narendorf, Benjamin Cooper, Paul R. Sterzing, Mary Wagner and Julie Lounds Taylor

What other infrastructure and surveillance needs must be met?

Prevalence and database: CDC reports 1 in 88 (1 in 54 boys) – 78% increase from 2002. NDAR expands to >30,000 subjects.

Sharing Heterogeneous Data: The National Database for Autism Research

Neuroinformatics *May 2012*

Dan Hall, Michael F. Huerta, Matthew J. McAuliffe, Gregory K. Farber

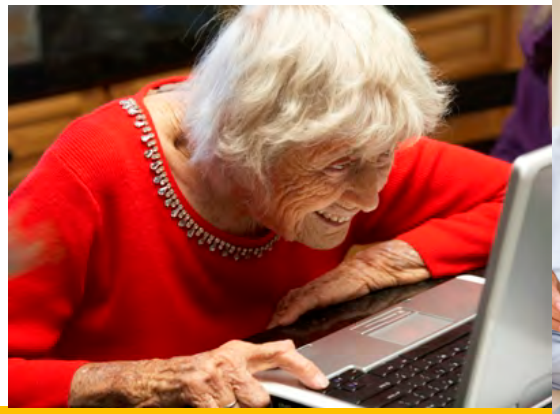
Autism News and Updates

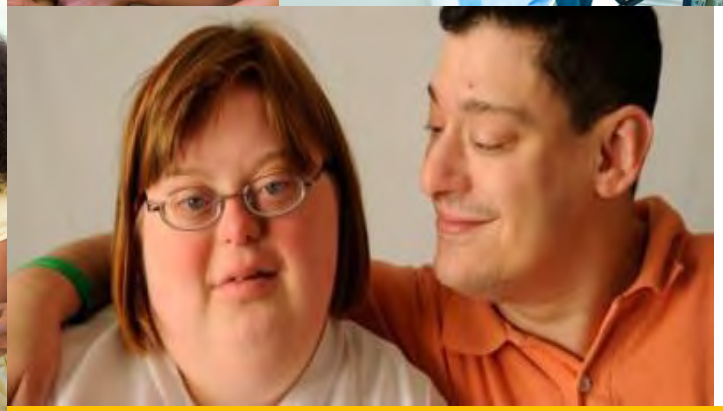
- NIH Autism Centers of Excellence (ACEs)
  - Continuation of the program
  - New awards to be announced this summer
- Health insurance coverage for autism therapies
  - Office of Personnel Management (OPM) changed Applied Behavioral Analysis (ABA) to a medical benefit
  - Allows insurance plans in the Federal Employee Health Benefit program to cover ABA therapy
- Seclusion and restraint
  - Department of Education recently released a Restraint and Seclusion Resource Document
  - Recent Department of Education data collection included seclusion and restraint, analysis

Autism News and Updates

- Wandering
  - ICD-9 code for wandering created by CDC and finalized in Oct. 2011
  - Questions related to wandering were included for the first time in the 2011 HRSA Children with Special Health Care Needs survey; analysis pending
  - Autism Speaks, Autism Research Institute, the Autism Science Foundation, and the Global Autism Collaboration partnered with IAN to launch a national family survey on wandering and published a report on findings
- DSM-V
  - Public comment period ended June 15 and revisions ongoing





Administration for Community Living

U.S. Department of Health and Human Services

"For too long, too many Americans have faced the impossible choice between moving to an institution or living at home without the long-term services and supports they need. The goal of the new ***Administration for Community Living*** *will be to help people with disabilities and older Americans live productive, satisfying lives." - Secretary Kathleen Sebelius*

Overview

- This new HHS Operating Division brings together the Administration on Aging (AoA), the Office on Disability (OD) and the Administration on Developmental Disabilities (ADD)
- This single agency is charged with developing policies and improving supports for seniors and people with disabilities.

Why Is This Important?

- The common interests of the aging and disability populations have been recognized at the local and state levels.
- The mechanisms for providing supports that facilitate community living have been brought together into agencies that serve both populations.
- Yet at the federal level, policy development, community outreach and program implementation related to aging and disability across the lifespan was fragmented across HHS.

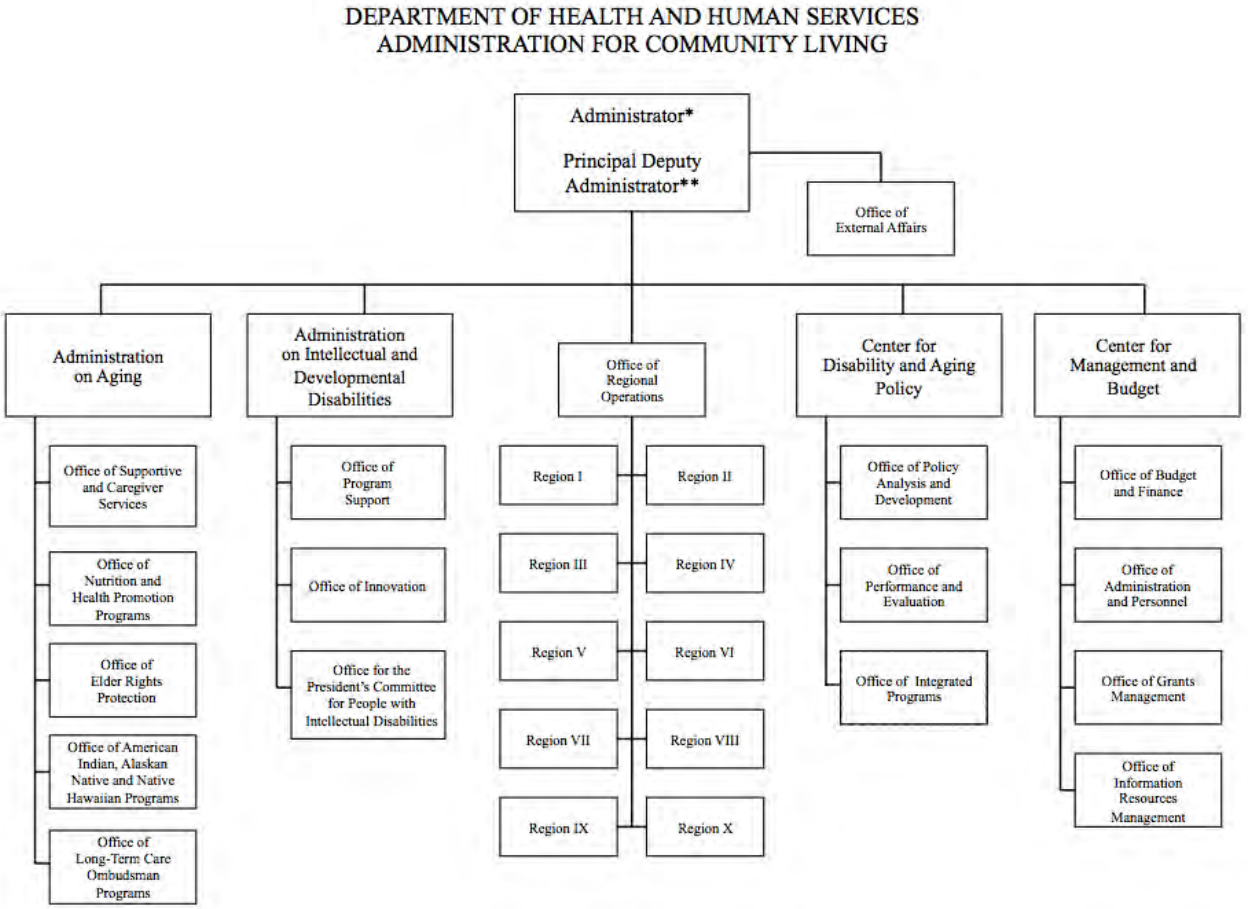
Background

- In 2009, on the 10th anniversary of the Supreme Court's landmark Olmstead decision, President Obama announced *the Year of Community Living.*
- He directed the HHS and HUD Secretaries to work together to identify ways to improve access to housing, community supports, and independent living for people with disabilities.

Background

- In 2009 HHS Secretary Sebelius established an interagency Coordinating Council co-led by the Director of the Office on Disability and the Assistant Secretary on Aging.
- Through the Community Living initiative, stakeholders and states have been engaged, investments made to improve access to housing and critical long-term services and supports; increase in communities that have Aging and Disability Resource Centers and enhanced state participation in the Money Follows the Person program.

Organizational Structure



*Also serves as the Assistant Secretary for Aging
**Also advises the Secretary directly on disability policy

Office of Special Education and Rehabilitative Services

LARRY WEXLER

DIRECTOR, RESEARCH TO PRACTICE DIVISION

Restraint & Seclusion: Key Concepts

- Purpose
- Clearance
- Safety
- All Children
- No evidence of Effectiveness

Restraint & Seclusion
Key Concepts

- Prevention
- Not Punishment
- Document
- No Harm

Restraint & Seclusion
Key Concepts

- Underlying Cause
- Effective Alternatives
- Mechanical-Drug-Medication

Restraint & Seclusion Key Concepts

- Department of Education firmly believes that one case of inappropriate use of restraint or seclusion—**is one case too many**

Restraint & Seclusion
Key Concepts

http://www2.ed.gov/policy/seclusion/restraints-and-seclusion-resources.pdf

Meeting of the IACC

Afternoon Agenda

2:15 **Update on the DSM-5 Criteria for ASD**

Susan E. Swedo, M.D.
Chief Pediatrics & Development Neuroscience Branch, NIMH
Chair, The DSM-5 Neurodevelopment Disorders Workgroup

2:30 **Insurance Coverage for Autism Treatments**

Stuart Spielman
Senior Policy Advisor and Counsel
Autism Speaks

Peter Bell, MBA
Executive Vice President of Programs and Services
Autism Speaks

An Update on the DSM-5 Recommendations for Autism Spectrum Disorder and Other Neurodevelopmental Disorders

Susan E. Swedo, M.D.
Chair, DSM-5 Neurodevelopmental Disorders Workgroup

DSM-5 Neurodevelopmental Disorders Workgroup (2007 - Present)

MEMBERS

- Gillian Baird
- Ed Cook
- Francesca Happe
- James Harris
- Walter Kaufmann
- Bryan King
- Catherine Lord
- Joseph Piven
- Rosemary Tannock
- Sally Rogers
- Sarah Spence
- Susan Swedo
- (Fred Volkmar)
- Amy Wetherby
- Harry Wright

ADVISORS

- Jim Bodfish
- Martha Denckla
- Maureen Lefton-Grief
- Nickola Nelson
- Sally Ozonoff
- Diane Paul
- Eva Petkova
- Daniel Pine
- Alya Reeve
- Mabel Rice
- Joseph Sergeant
- Bennett & Sally Shaywitz
- Audrey Thurm
- Keith Widaman
- Warren Zigman

DSM-5 Makes Headlines

- NY Times – "New Definition of Autism Will Exclude Many"
  - Specifically, 35% of "high-functioning" and "Asperger disorder"
  - Subsequently quoted as "New Criteria Will Deny Services to 65% of Individuals with Autism"
- "Autism Statistics Worsen & Officials Want to Fudge the Numbers"
- Autism Spectrum Disorder – "Diagnostic Disaster"

Concerns about ASD in DSM-5

- **Sensitivity has been "sacrificed" in order to improve specificity**
  - Social communication domain
  - Restrictive interests and repetitive behaviors domain
- **Merging Asperger disorder (and PDD-NOS) into autism spectrum disorder results in loss of identity and ignores uniqueness of Asperger dx**
- **Pre-/post DSM-5 research studies won't be comparable**

Proposed Changes to the Pervasive Developmental Disorders (PDD)

- Three diagnostic domains will become two (Social communication and Restricted, repetitive behaviors)
- Rett Disorder and other etiologic subgroups will be described by use of a Specifier: Associated with Known Medical or Genetic Condition or Environmental Factor
- PDD will be replaced by Autism Spectrum Disorder (ASD)
- Individual diagnoses will be merged into a single, behaviorally defined disorder

Examples of DSM-IV and DSM-5 Criteria Changes

For subcriterion A.3,

DSM-IV checklist item is "failure to develop peer relationships and abnormal social play."

DSM-5 recommendations include higher-order impairments of "difficulties adjusting behavior to suit different social contexts.

Examples of DSM-IV and DSM-5 Criteria Changes

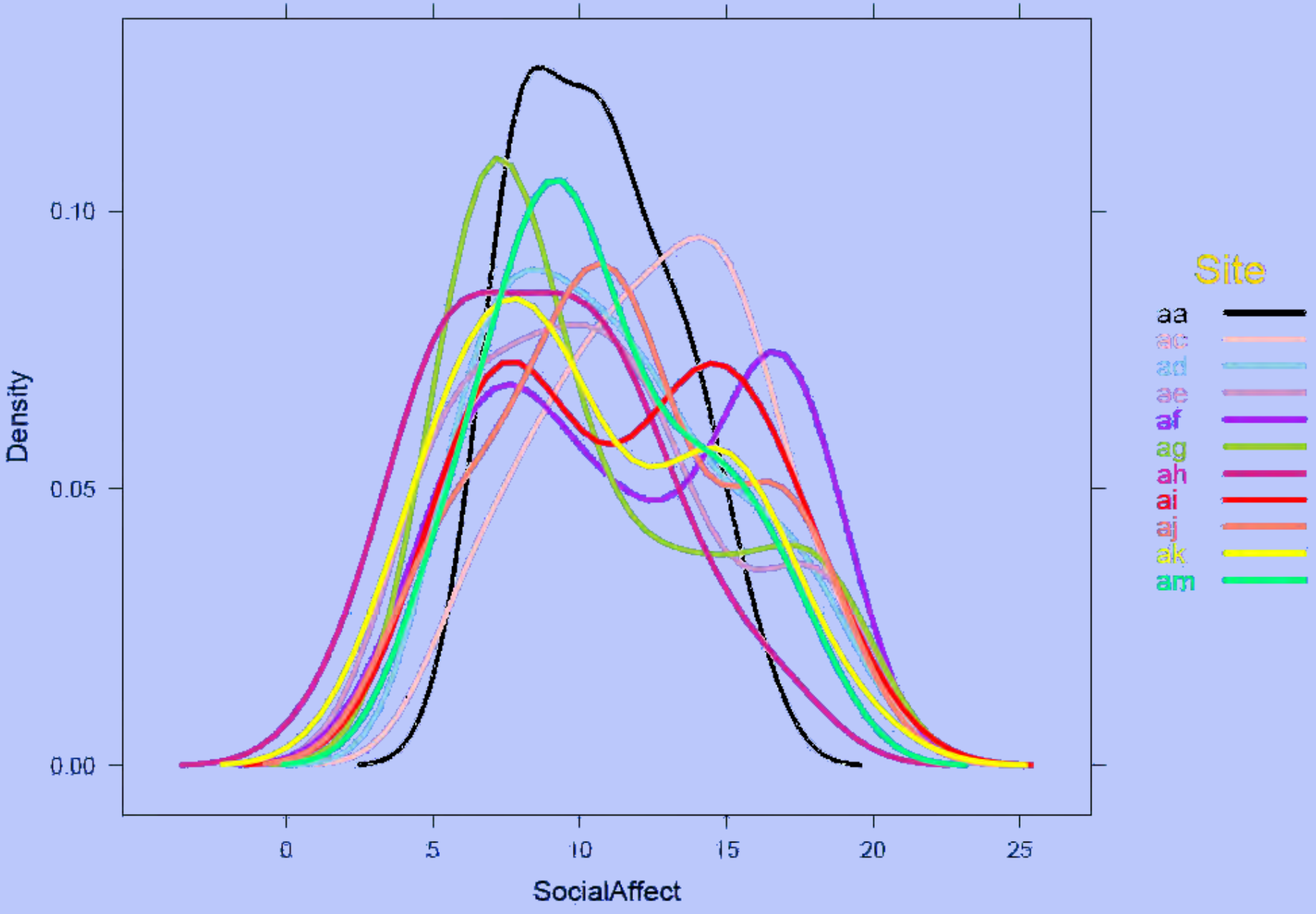
For criterion C, DSM-IV requires that symptoms begin prior to the age of 3 years.

The *DSM-5* requires that symptoms begin in early childhood, with the caveat that "symptoms may not be fully manifest until social demands exceed capacity" (during middle-school years, later adolescence, or young adulthood).

Decision to include Asperger Syndrome & PDD-NOS within one ASD diagnosis

- **Scientific validity**
  - **Lack of specificity and sensitivity in separating the diagnoses**
  - **Lack of accurate historical information about very early language development put emphasis on current speech (trainable)**
  - **Overlap in samples when VIQ controlled**
- **Consideration of access to services**

ADOS Social Affect

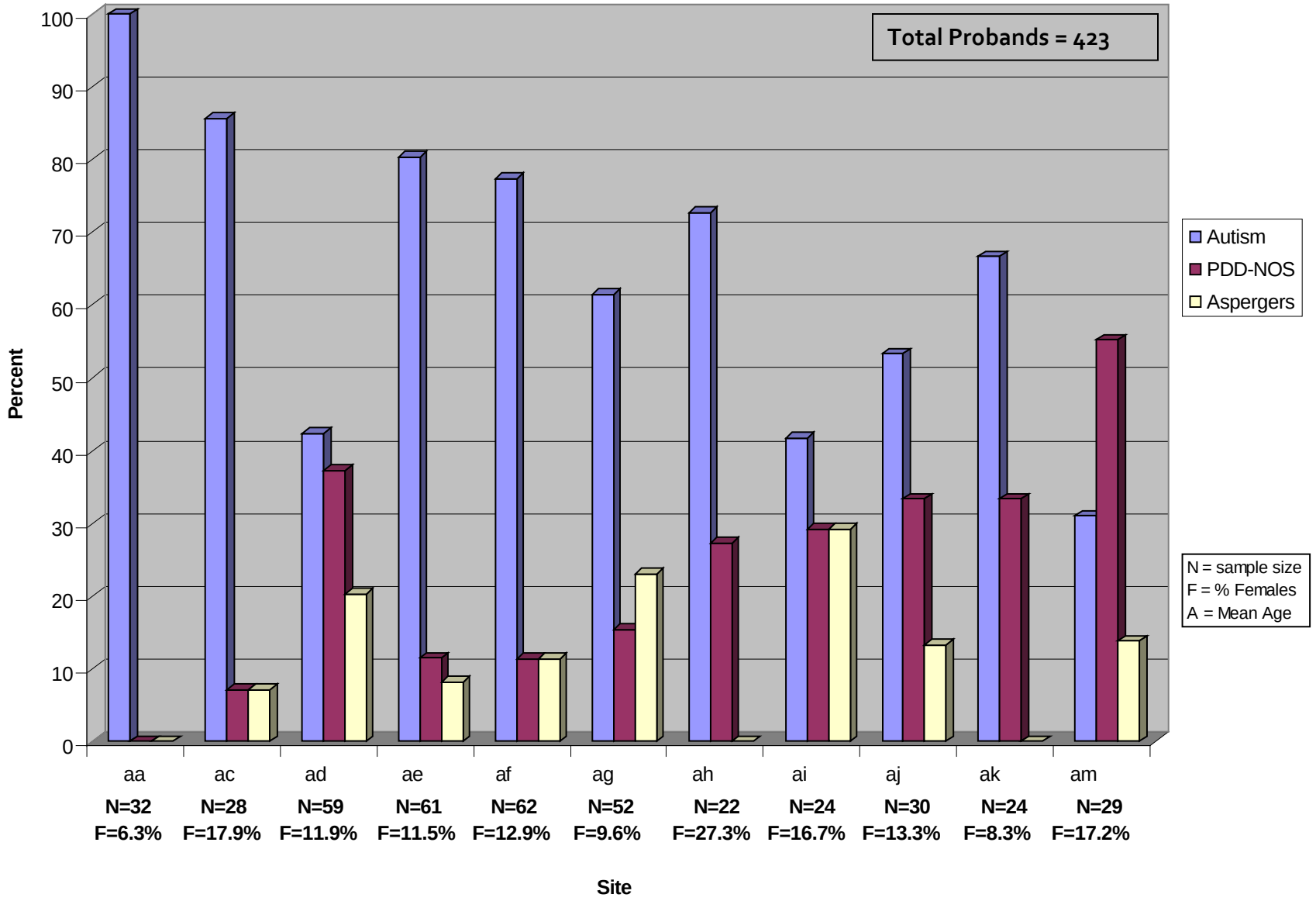


Data from Simons Collection

- Over 2200 validated singletons with ASD;
- 8500 family members (two biological parents and, in most cases, at least one unaffected sibling) with DNA and intensive behavioral and neuropsychological phenotyping

- Recruited from 12 sites in the US and Canada

ASD Distribution of Probands



Single Spectrum but Significant Individual Variability

- **Severity of ASD Symptoms**
- **Pattern of Onset and Clinical Course**
- **Etiologic factors**
- **Associated conditions**
- **Individual weaknesses and strengths**

CLINICIANS WILL BE ENCOURAGED TO DESCRIBE THESE DETAILS WITH DIAGNOSTIC SPECIFIERS

Sensitivity and Specificity of DSM-5 Criteria for Autism & Related Disorders

DSM-5 FIELD TRIALS	Completed V1	Completed V2
Pediatric Sites:		
Stanford	**158**	**148**
The Children's Hospital	216	193
Baystate Medical Center	**164**	**145**
Columbia/Cornell	127	120
Pediatric Sites	**665**	**606 (293)**

Sensitivity and Specificity of DSM-5 Criteria for Autism & Related Disorders

	NONE		Autistic Disorder	Asperger Disorder	PDD-NOS	TOTAL
DSM-IV	214		35	21	23	79
DSM-5 ASD	19		31	16	17	83
DSM-5 SCD	10		4	2	1	17
No DSM5 ASD/SCD	185 (86%)		0	3	5	

NOTE: Some DSM-IV cases "lost" their diagnosis with DSM-5 criteria, but overall, there was an increase in ASD cases. Further, when SCD cases are added, there was a 14% increase in new cases of ASD/SCD.

Summary of DSM-5 Field Trials Data

Specificity and Sensitivity of DSM-5 ASD Criteria are comparable to DSM-IV.

ND Workgroup will examine validity or DSM-5 Criteria from archived patient interviews.

For More Information

American Psychiatric Association

www.dsm5.org

Neurodevelopmental Disorders

Autism Spectrum Disorder in DSM-IV

Currently, OR BY HISTORY, must meet criteria A, B, C, and D

A. Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifest by all 3 of the following:

1. Deficits in social-emotional reciprocity
2. Deficits in nonverbal communicative behaviors used for social interaction
3. Deficits in developing and maintaining relationships

B. Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the following:

1. Stereotyped or repetitive speech, motor movements, or use of objects
2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change
3. Highly restricted, fixated interests that are abnormal in intensity or focus
4. Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment;

C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities)

D. Symptoms together limit and impair everyday functioning.

A. Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifest by all 3 of the following:

1. **Deficits in social-emotional reciprocity**; ranging from abnormal social approach and failure of normal back and forth conversation through reduced sharing of interests, emotions, and affect and response to total lack of initiation of social interaction,
2. **Deficits in nonverbal communicative behaviors used for social interaction**; ranging from poorly integrated- verbal and nonverbal communication, through abnormalities in eye contact and body-language, or deficits in understanding and use of nonverbal communication, to total lack of facial expression or gestures.
3. **Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers**); ranging from difficulties adjusting behavior to suit different social contexts through difficulties in sharing imaginative play and in making friends to an apparent absence of interest in people

2. All individuals must have or have had restricted interests and repetitive behaviors (in at least 2 of 4 domains)

1. **Stereotyped or repetitive speech, motor movements, or use of objects** (e.g. simple motor stereotypies, echolalia, repetitive use of objects, or idiosyncratic phrases).
2. **Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change** (e.g., motoric rituals, insistence on same route or food, repetitive questioning or extreme distress at small changes).
3. **Highly restricted, fixated interests that are abnormal in intensity or focus**; (e.g. strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
4. **Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment**; (e.g. apparent indifference to pain/heat/cold, adverse response to specific sounds/textures, smelling or touching of objects, fascination with lights or spinning objects).

Recent Developments in Insurance Coverage for Individuals with Autism Spectrum Disorders

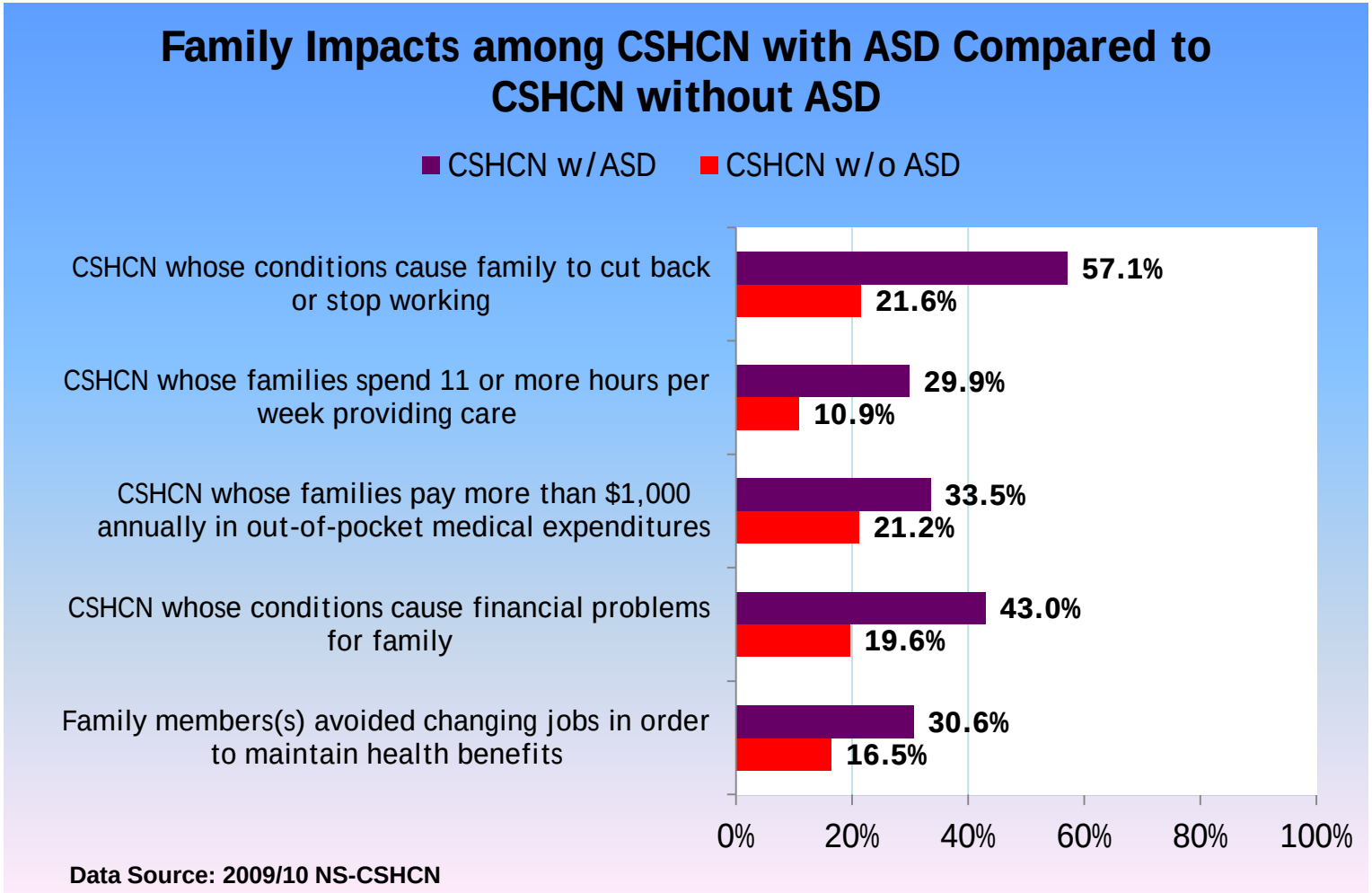
Interagency Autism Coordinating Committee
Washington, DC
July 10, 2012

Health Care in America

"a fundamental principle that here in America -- in the wealthiest nation on Earth -- ***no illness or accident should lead to any family's financial ruin***."

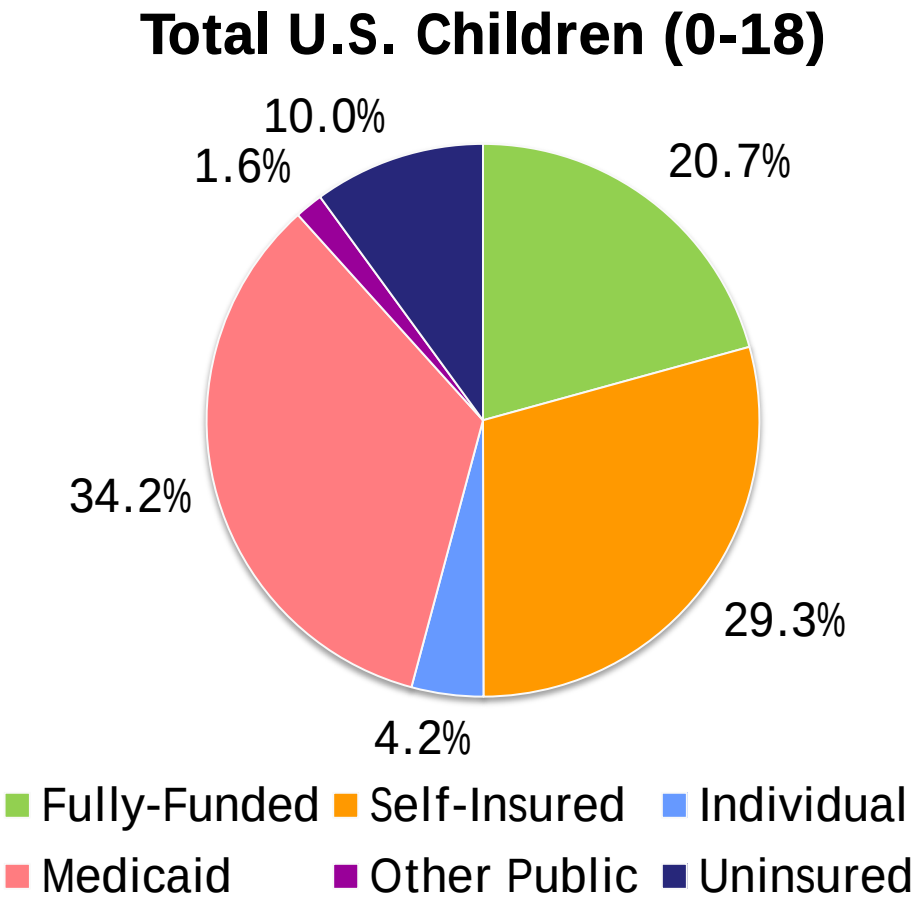
Source: Remarks by President Obama on Supreme Court Ruling on the Affordable Care Act, June 28, 2012.

Health Care with Autism



Source: Child and Adolescent Health Measurement Initiative (2012). "National Profile of Children with Special Health Care Needs and Autism Spectrum Disorders: Key Findings from the 2009/10 NS-CSHCN and 2007 NSCH."

Types of Insurance Coverage

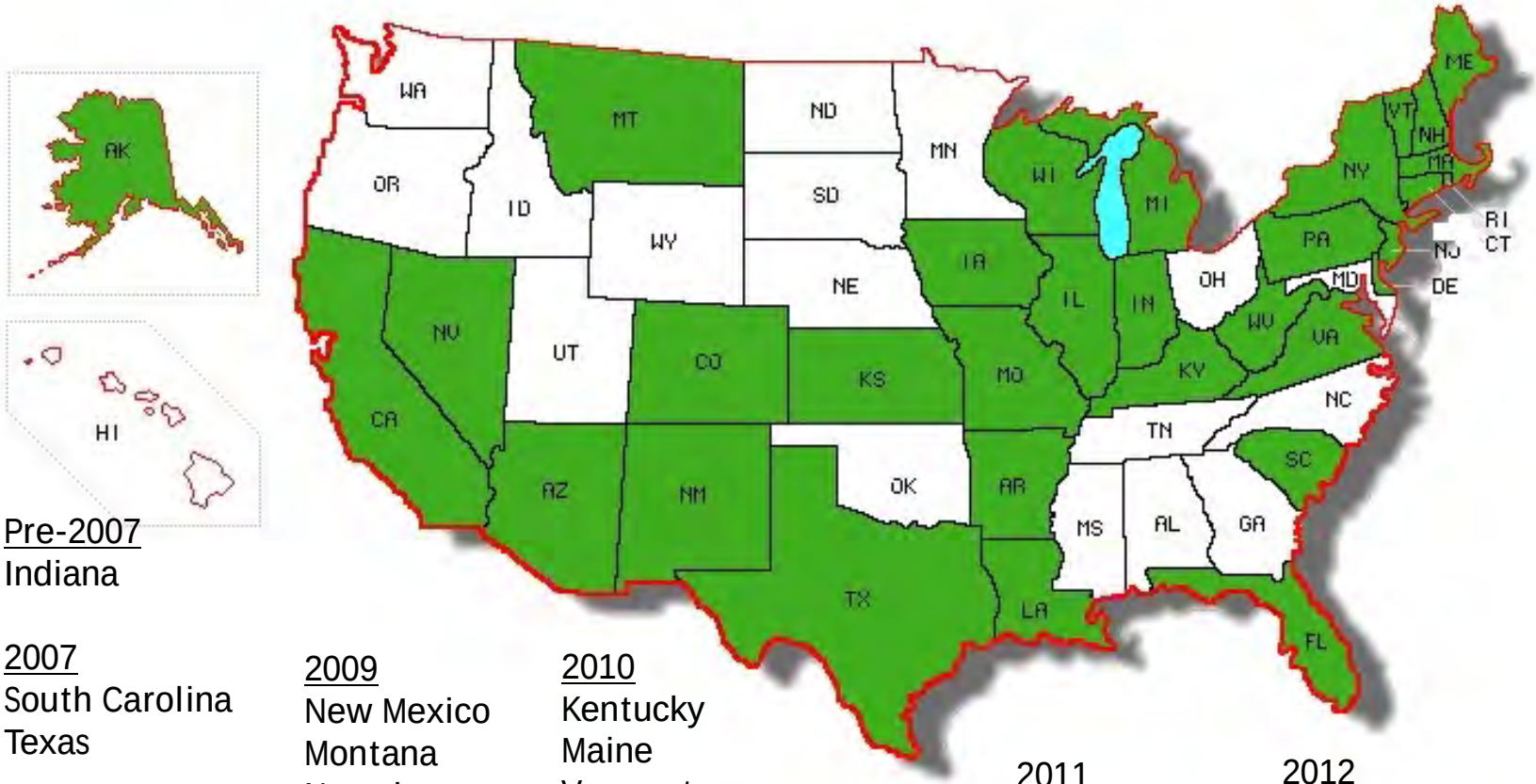


The Kaiser Family Foundation, *statehealthfacts.org*. Data Source: Health Insurance Coverage of Children 0-18, states (2009-2010), U.S. (2010), accessed June 29, 2012.

Autism Insurance Reform

- Fully Funded Plans (Employer-Sponsored and Individual)
  - State-based autism insurance reform
- Self-Funded Plans (regulated by ERISA)
  - More self-insured employers are adopting autism benefits
- Medicaid
  - Ongoing litigation over Early and Periodic Screening, Diagnosis and Treatment (EPSDT) Program
- Public Plans (Federal and State)
  - OPM recognized ABA as medical therapy
  - Legislation to make behavioral health treatment for autism part of TRICARE basic plan
- Affordable Care Act
  - Behavioral Health Treatment as an Essential Health Benefit

State Autism Insurance Reform



Pre-2007
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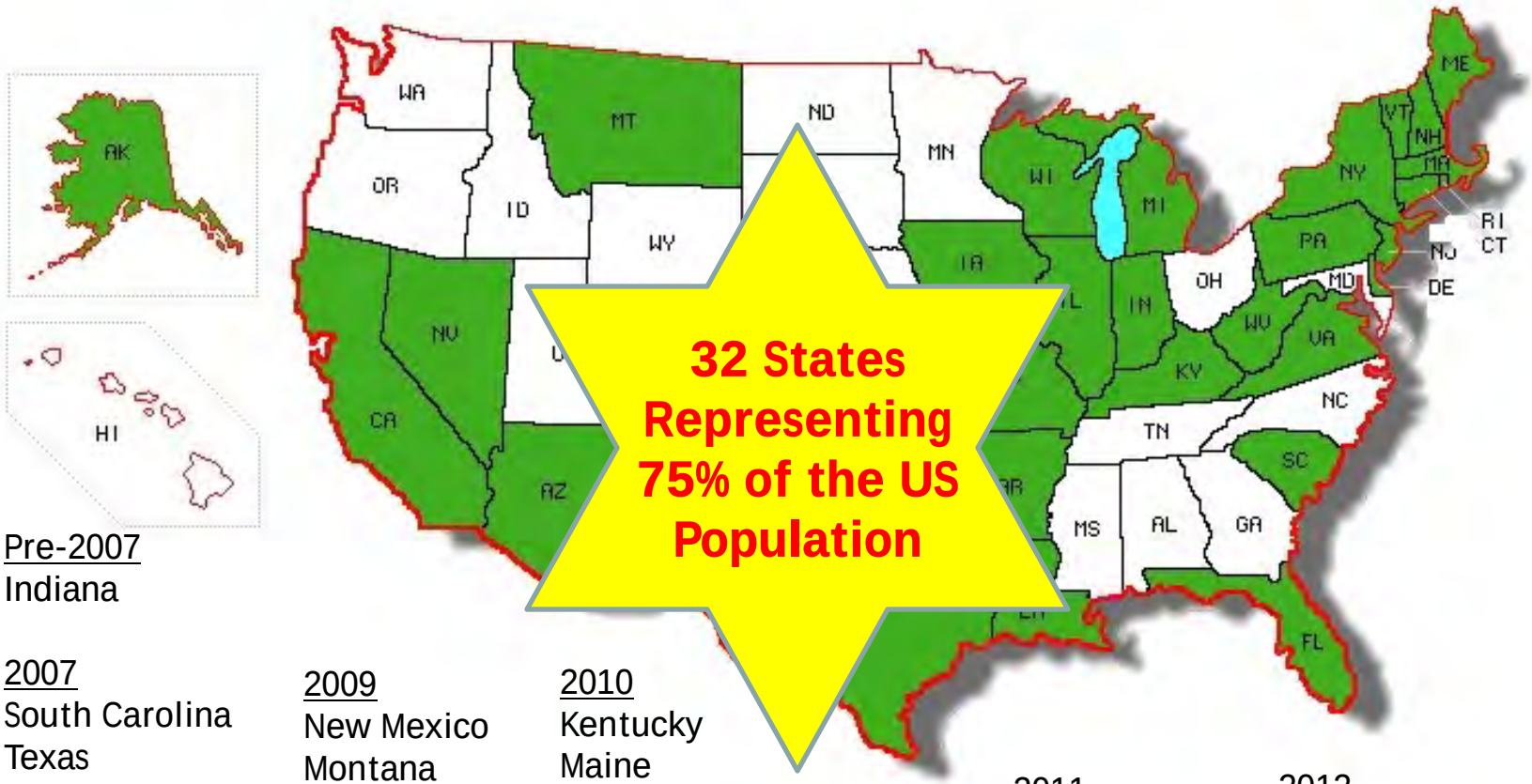
Virginia
Rhode Island
California
New York

2012
Michigan
Alaska
Delaware

State Autism Insurance Reform



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New York

2012
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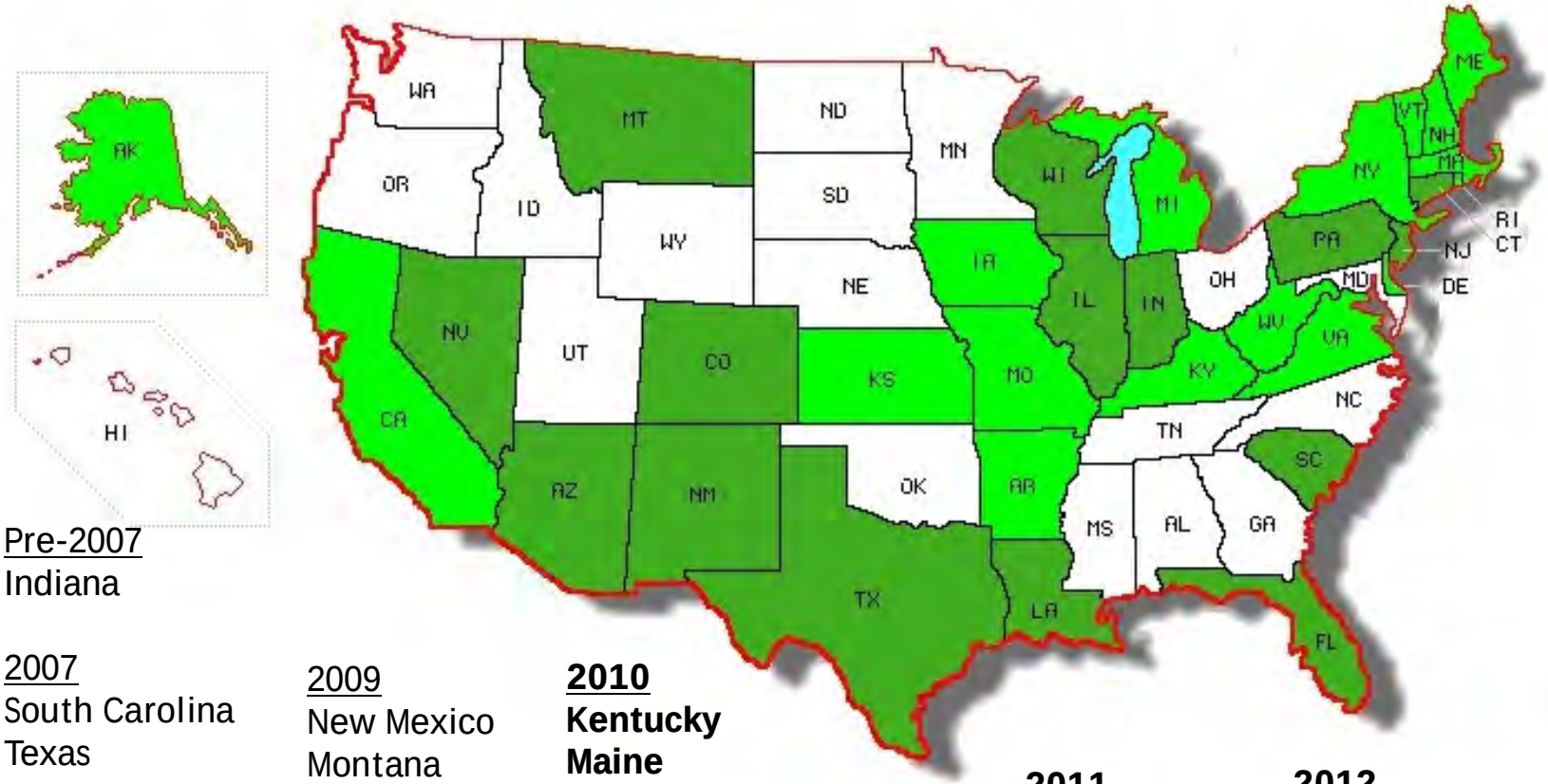
Alaska
Delaware

Post-ACA Enacted Laws (17 states)



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New York

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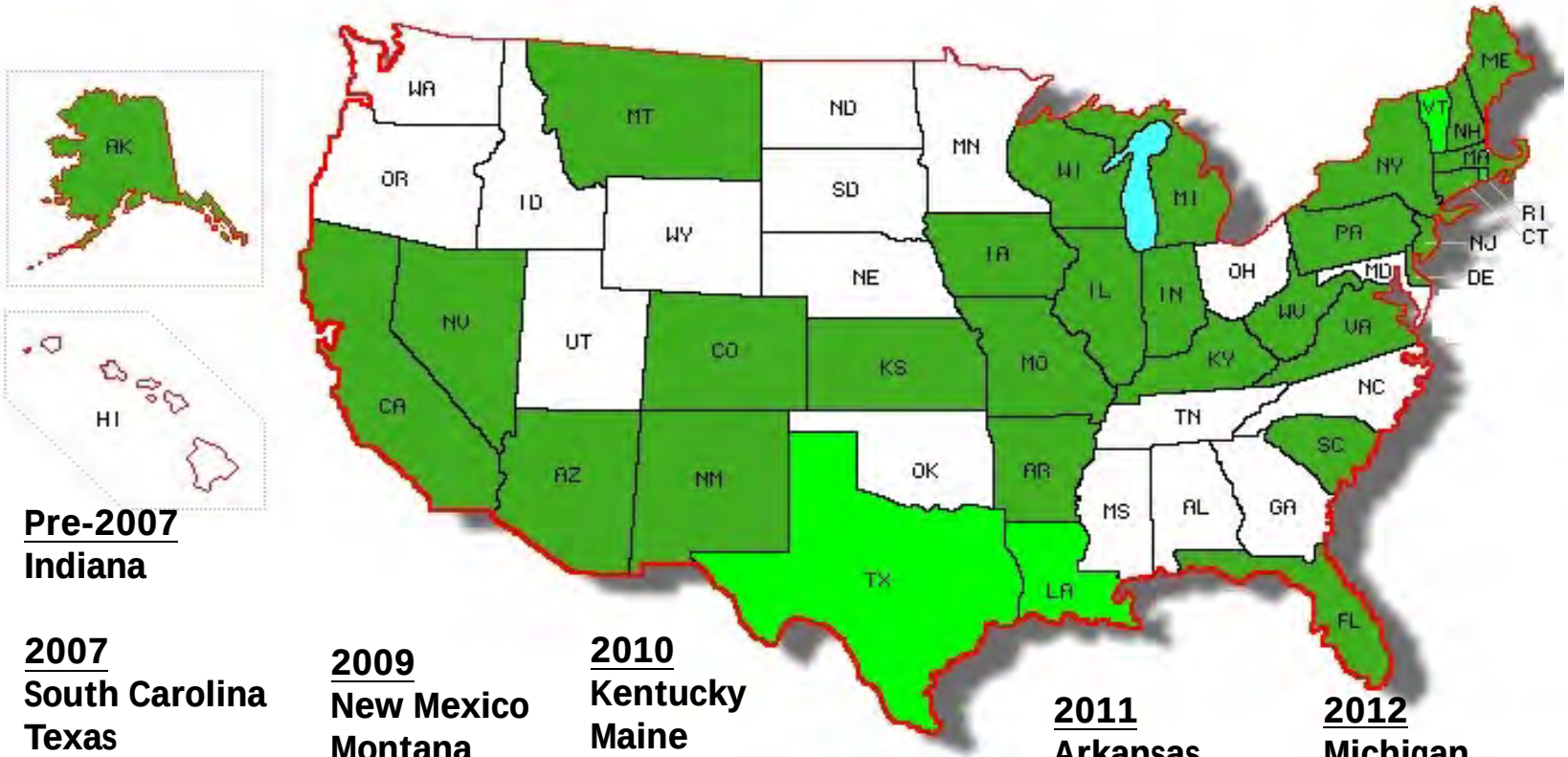
Alaska
Delaware

State Expansion Laws (4 states)



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Missouri
New
Hampshire
Massachusetts

2011
Arkansas
West
Virginia
Virginia
Rhode Island
California
New York

2012
Michigan
Alaska
Delaware

Self-Funded Plans with Autism Benefit

- Microsoft
- Home Depot
- Intel
- Capital One
- Eli Lilly
- Deloitte
- The Ohio State University
- Mayo Clinic
- HealthCentral
- Lexington Medical Center
- University of Minnesota
- Harvard University
- Progressive Group
- Time Warner
- City of Atlanta
- Oracle
- Adobe Systems
- Yahoo!
- Cisco
- DTE Energy
- Princeton University
- Children's Mercy
- Aspect Software
- Partners Healthcare

Medicaid Litigation

- Medicaid mandated, optional, and waiver services provide a range of benefits to individuals with ASD.
- Recent cases have focused on ABA as a benefit under the EPSDT Program:
  - *Parents League for Effective Autism Services v. Jones-Kelley (2009)*, the U.S. Court of Appeals for the Sixth Circuit affirmed a lower court ruling that **ABA was a covered service under EPSDT**.
  - *K.G. v. Dudek (2012),* the U.S. District Court for the Southern District of Florida found that **ABA was a required treatment service under EPSDT**, rejecting the state's argument that ABA is experimental under Florida law.

Federal Employees Health Benefits (FEHB) Program

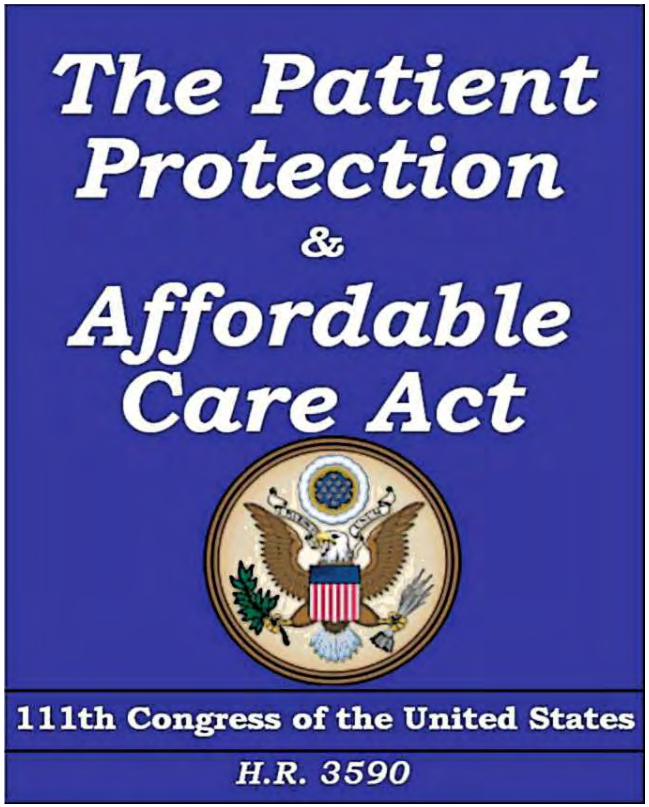
- Office of Personnel Management (OPM) provides health insurance coverage to eight million federal employees, retirees, and dependents through FEHB.
- OPM Benefit Review Panel concluded sufficient evidence exists to categorize ABA as a medical therapy, not just an "educational intervention."
- In April 2012, OPM issued guidance to insurers who participate in the FEHB Program for policies that will be renewed or issued starting in 2013.
- OPM decision **does not require** the insurers to cover ABA, but rather **allows them to offer** the coverage as it does many other medical treatments.

TRICARE Autism Benefit

- Currently, autism behavioral benefits are capped at $36,000/year and restricted to active duty military personnel through ECHO Program.
- Caring for Military Kids with Autism Act (H.R. 2288) introduced to make medically necessary behavioral health treatments available to all military dependents through basic TRICARE program.
- Amendment to National Defense Authorization Act (NDAA) approved by the House in May 2012.
- Senate Armed Services Subcommittee on Personnel held a hearing on June 21st to consider coverage issues. Floor vote on the Senate version of NDAA is pending.

Affordable Care Act (ACA)

- Coverage for certain preventive services are required: screening for autism, developmental delays, and other disabilities.
- Prohibits denials based on preexisting conditions.
- Dependents can remain on parents' health plan until age 26.
- Essential Health Benefits (EHB) must include "Mental health and substance use disorder services, **including behavioral health treatment**."



Future ACA Challenges

In 2014 state health exchanges will begin operation. Uncertainties remain about the quality of care exchange plans will provide to people with ASD:

- Habilitative services, a part of the EHB, are not defined.
- States must defray the cost of benefits mandated after 2011 that are part of exchange plans.
- Notwithstanding congressional intent, coverage of behavioral treatment for autism has not been resolved.

Senator Robert Menendez Introduces Autism Insurance Reform Amendment in Senate Finance Committee (September 25, 2009).

Meeting of the IACC

Afternoon Agenda – Cont'd

2:40 **Autism and Epilepsy: Clinical Profile across the Lifespan**

Geraldine Dawson, Ph.D.
Chief Science Officer
Autism Speaks

2:50 **Update on NIH/Autism Speaks CURE Meeting on Epilepsy and Autism**

Deborah Hirtz, M.D.
Program Director
Office of Clinical Research
National Institute of Neurological Disorders and Stroke

3:00 **Break**

Autism and Epilepsy:

Clinical profile across the lifespan

Presentation for the Interagency Autism Coordinating Committee

July 10, 2012

Geraldine Dawson, Ph.D.

Chief Science Officer, Autism Speaks

Professor, Department of Psychiatry, UNC Chapel Hill

Seizure disorders affect 15-30% of children with ASD

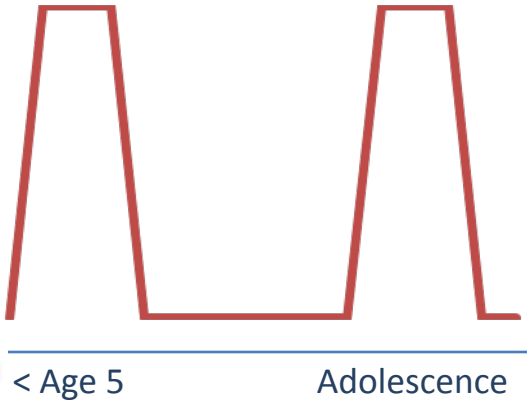
Prevalent in ASD

- Epilepsy
- Epileptiform abnormalities

Impact

- Poorer outcomes than ASD individuals without epilepsy
  - Adaptive outcomes
  - Behavioral outcomes
  - Social outcomes
- Increased behavioral challenges
- Increased motor problems
- Increased mortality rate

- Age of onset is bimodal
- Higher prevalence of epilepsy in children with
  - Syndromic autism
  - Motor impairments
  - Intellectual disability
  - Females (often associated with cognitive impairments)
- Relationship of autistic regression to epilepsy is not definitive
- Children with infantile spasms more likely to develop autism



Tuchman et al. 2009, Plauche Johnson et al. 2007, Tuchman et al. 2010; Tuchman & Cuccaro 2011; Maski et al. 2011

The clinical profile of autism with epilepsy

Epilepsy in autism: features and correlates

Patrick F. Bolton, Iris Carcani-Rathwell, Jane Hutton, Sue Goode, Patricia Howlin and Michael Rutter

BJPsych The British Journal of Psychiatry (2011) 198, 289–294. doi: 10.1192/bjp.bp.109.076877

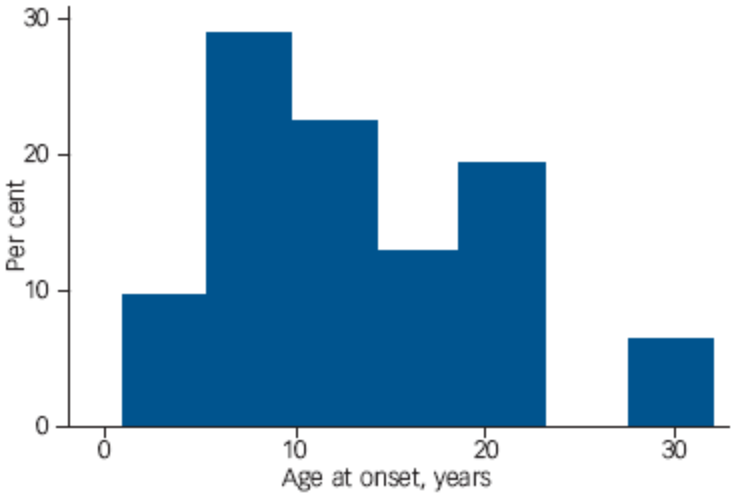


Fig. 1 Age at onset of seizures.

Bolton et al., 2011

- 175 individuals followed through 21 years
- 22% developed epilepsy (after 10 yrs for most)
- More common in females than males
- Epilepsy associated with lower nonverbal IQ, lower verbal abilities and social skills

Amiet et al., 2008

- Meta-analysis of 24 studies on autism (N = 2112) and epilepsy (N = 1530)
- Epilepsy present in 21.5% of patients with autism and ID vs. 8% in patients with autism without ID
- Girls with autism more likely to have epilepsy

# Autism Treatment Network
# Rates of epilepsy
N = 4,321

	Autism N=2895	Aspergers N=369	PDD N=1057	ASD N=4321
NO	56.9%	7.6%	21%	85.5%
YES	10.1%	0.9%	3.5%	14.5%
TOTAL	67%	8.5%	24.5%	100%

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TOTAL	67%	8.5%	24.5%	100%

Autism Treatment Network
Rates of epilepsy by IQ

N = 4,321

	<70 N=2370	>70 N=1951	Total N=4321
No	46.3%	39.2%	85.5%
Yes	8.5%	5.9%	14.5%
Total	54.8%	45.3%	100%

Epilepsy and sleep disturbance

- Epilepsy is associated with sleep disturbances in children with and without ASD.
- Recent review of 17 studies on sleep and ASD (Hollway and Aman, 2011) found that epilepsy and other medical conditions are associated with disrupted sleep in individuals with ASD.
- Sleep disturbances are associated with:
  - Increased aggressive behavior, irritability, and inattentiveness
  - Sleep disturbance, rather than seizure severity, may contribute to difficulties with irritability and attentiveness (Becker et al., 2004)

Clinical evaluation and treatment

- All seizure types reported, but complex partial seizures are most frequent; signs of CPS are similar to some ASD behaviors (unresponsive to name, repetitive movements).
- EEGs are helpful but difficult to perform. Prolonged/overnight studies are more sensitive than routine ones.
- High rates of epileptiform EEGs have been reported in children with ASD without clinical epilepsy; clinical significance is unclear.
- Evaluation of genetic etiology is important because seizures are more common in syndromic forms of ASD.
- Anticonvulsant treatment choice is related to type of seizure, EEG findings, and tolerability of medication.

Common neurological co-morbidities in autism spectrum disorders
Kiran P. Maskia, Shafali S. Jesteb and Sarah J. Spencea
Current Opinion in Pediatrics 2011, 23:609–615

Current Standards for Treatment and Management

Current Standards

- AAP Identification and Management of ASD
- ASD Practice Parameter

(American Academy of Neurology and Child Neuro)

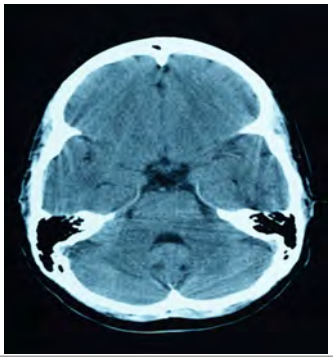
- AAP Autism Tool Kit

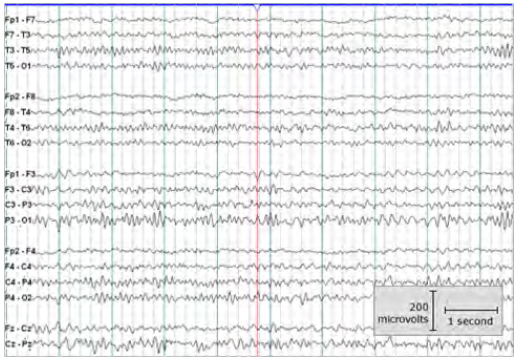
Limitations

- Need more information on evaluation of epilepsy
- Autism Tool Kit is resource but not guideline

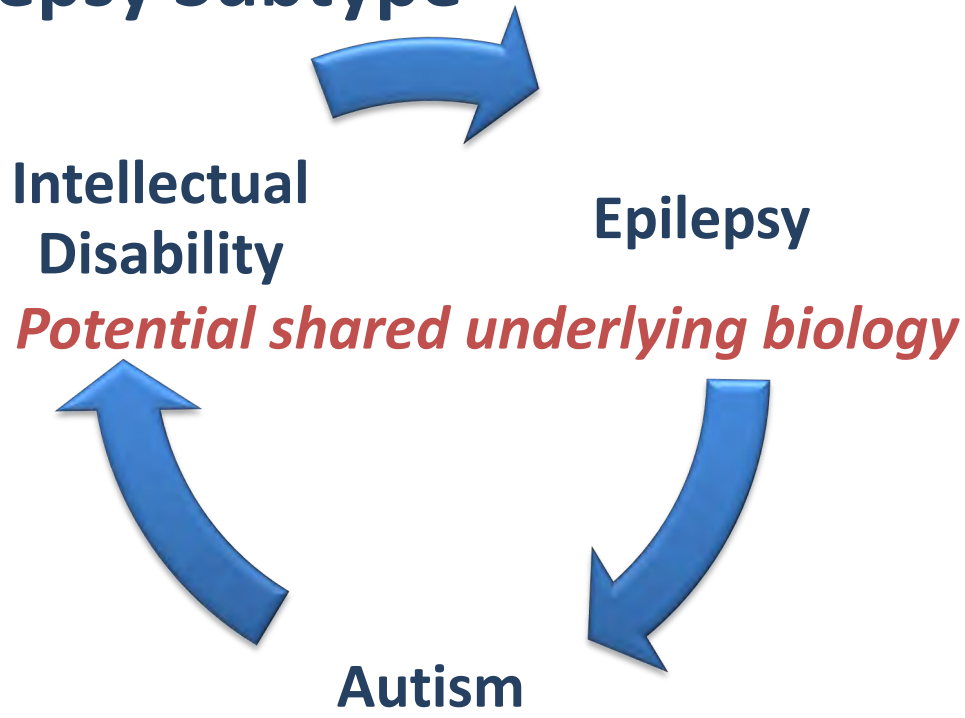
ATN/AIR-P Activities

- **Clinical Practice Guidelines for EEG**
- **Clinical Practice Guidelines for Neuroimaging testing**
- **To be published in 2013**





Autism-Epilepsy Subtype



- Identifying this shared biology can have consequences for identifying
  - common genetic and other types of risk factors
  - common biological targets for treatment

Tuchman et al. 2009, Tuchman et al. 2010; Tuchman & Cuccaro 2011

NINDS Autism and Epilepsy Workshop
May 29-30, 2012
Bethesda Maryland

Cosponsored by NICHD, Autism Speaks and CURE

AS-CURE-ILAE: Autism-Epilepsy Scientific Research Synergies from a Global Perspective, December 2010

- Define scope of problem
- Need to involve researchers from both fields
- Plan for next steps.

Topics for May 2012 NIH workshop

- Who are these children?
- What causes this to happen?
- Are there environmental/immunologic risk factors?
- What can we learn about mechanisms from syndromes with both features?
- What do we know and need to know about neuroimaging, neuropathology, and neurophysiology?
- How do we design studies unique to this population?
- What resources are there for clinical research?
- What are the short and long- term goals, next steps?

Who are these children- Epidemiology

Epilepsy in those with ASD (Tuchman and Rapin 2002):

- Peak in childhood more associated with intellectual disability, peak in adolescence less so
- Cumulative risk 67% by age 10 in autism +severe MR+CP
- 27% with autism and severe MR
- 8% with autism only

ASD in those with epilepsy (Berg 2011):

- Normal cognition- 2.2% with ASD
- MR- 10.6% WITH ASD

What causes this to happen?

- ASD, Epilepsy and intellectual disability could result from the same mechanisms, resulting in an abnormality of synaptic plasticity, or abnormalities of excitatory and inhibitory balance, e.g. TSC, Fragile X, neuroligin mutations
- Early in life there could be either delayed maturation of inhibitory receptors or early maturation of excitatory receptors
- Seizures may result in abnormalities of neurotransmission that could contribute to learning and social behavioral deficits

Infantile spasms

- Early epilepsy syndrome where common outcome is intellectual disability and autism
- Could be used to study how early intervention could prevent the autistic symptoms

EEG and autism

- Epileptiform EEGs (with interictal epileptiform discharges), even without seizures, may impact cognition and behavior, based on extensive animal data and limited human data.
- EEG endophenotypes exist for epilepsy but not clear yet whether they exist in ASD
- Genetic factors may be operant in EEG endophenotypes for autism but not yet identified. Several models were proposed. Overlap of genes and gene pathways may be illuminating

Sleep issues also related

- Significant interdependent relationships among sleep, IEDs, and seizures which impact neural circuitry output (cognition and behavior).
- Sleep abnormalities and IEDs have both regional and long distant effects on neural circuits/functional connectivity.

Possibility for intervention or prevention trials

- Patients with ASD and epileptiform EEGs, without seizures or with well-controlled seizures, could be subjects in a prospective, randomized, double-blind, placebo-controlled trial.
- Possible interventions include valproate, lamotrigine or oral steroids. (Risperidone as an active control, rather than placebo, was also discussed.)
- Primary endpoint could be improvement in language or behavior, compared with baseline. Secondary endpoints could include reduction in EEG spikes, compared with baseline, confirmed by central EEG review.

Designing clinical studies unique to this population

- Animal models not effective as they should be.
- Can EEG or functional MRI be used to identify intellectual disability?
- EEG can identify at risk groups but is not a primary outcome, potentially can be used to measure connectivity.
- Need to appreciate the common comorbidities. Treatment trials need to be applicable to all.

Resources for clinical research

- The potential for use of stem cells as a clinical research resource
- NIH approaches to brain tissue banking
- Autism Tissue program
- Databases and managed care
- Registries- autism speaks treatment network
- NDAR
- Christine database for epilepsy

Short term goals- opportunities for sharing resources

- Look for overlaps in both autism databases and epilepsy databases
- Integration of existing clinical, genomic and imaging datasets
- Look at populations with autism to understand what epilepsy does to the phenotypes; what kind of epilepsy do autistic children have? How can we better characterize?
- In single gene variants can try to modify disease, may later benefit more people.
- Identification of novel drug targets

Long term goals

- Integration of the two expertises and fields
- Search for shared mechanisms. Need to study commonalities at the genetics and neurological level; neural networks that are affected.
- Search for genomic and environmental factors for both
- Development of treatments that are disease-preventing; the objective is curative therapy.
- Clinical trials to develop evidence for best treatments; test combinations of behavioral and drug therapies

Summary

- Benefit to studying both disorders- understanding underlying mechanisms
- Also benefit to intervention and treatment plans, addressing the two related conditions.
- Follow-up plans for collaborative research

Meeting of the IACC

Break

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Meeting of the IACC

Afternoon Agenda – Cont'd

3:15 **IACC Business**

Susan A. Daniels, Ph.D.
Acting Director
Office of Autism Research Coordination, and
Executive Secretary, IACC

OARC/IACC Updates – New Document Releases

- 2011 IACC Summary of Advances
- 2010 IACC ASD Research Portfolio Analysis Report
- IACC/OARC Portfolio Analysis Web Tool
- IACC/OARC ASD Research Publications Analysis

Meeting of the IACC

Afternoon Agenda

3:15 **IACC Business – Cont'd**

Susan A. Daniels, Ph.D.
Acting Director
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Executive Secretary, IACC

Planning Future Committee Activities

- IACC Subcommittees and Workgroups
- 2012/2013 IACC Strategic Plan Update
- 2012 IACC Summary of Advances
- 2011 IACC Portfolio Analysis
- IACC Workshop

Meeting of the IACC

OARC/IACC Update: New Documents and Web Releases

Susan A. Daniels, Ph.D.
Acting Director, Office of Autism Research Coordination
National Institute of Mental Health
Executive Secretary, IACC
IACC Full Committee Meeting – July 10, 2012

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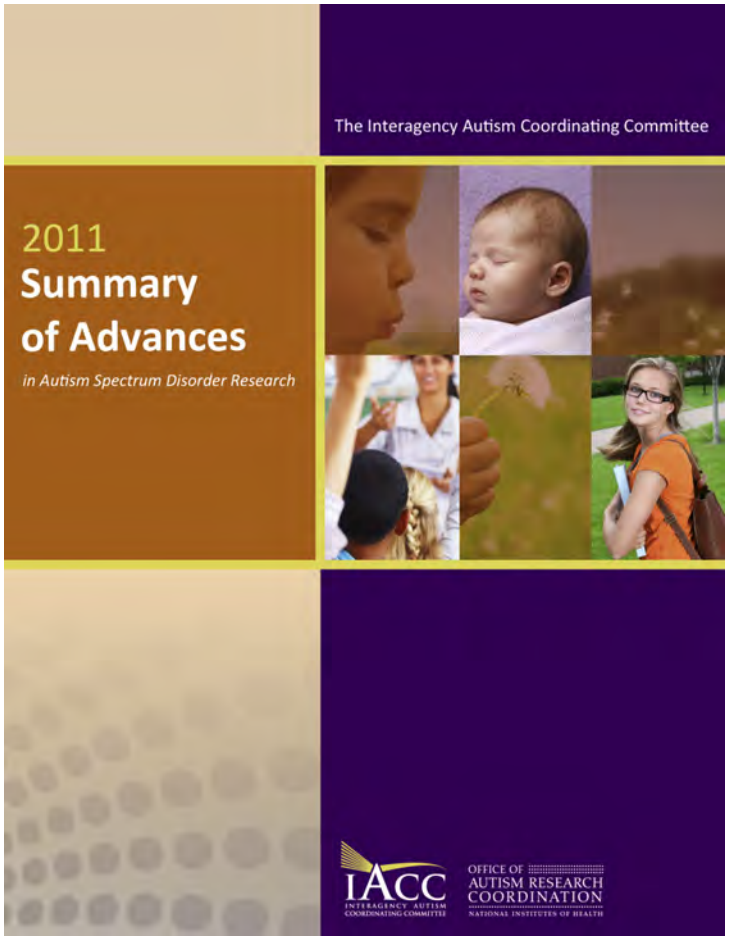
2011 Summary of Advances



- Released in April 2011

- The IACC identified 20 research findings and associated peer-reviewed articles published in 2011 that they felt reflected the most significant advances in ASD biomedical and services research.

- Lay-friendly summaries of research findings

- 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.

Publications Selected for 2011 IACC Summary of Advances

Q1 **DIAGNOSIS**

- Disrupted neural synchronization in toddlers with autism
- Detecting, Studying, and Treating Autism Early: The One-Year Well-Baby Check-Up Approach

Q2 **BIOLOGY**

- Mutations causing syndromic autism define an axis of synaptic pathophysiology
- Absence of CNTNAP2 leads to epilepsy, neuronal migration abnormalities, and core autism-related deficits
- Protein interactome reveals converging molecular pathways
- Transcriptomic analysis of autistic brain reveals convergent molecular pathways

Publications Selected for 2011 IACC Summary of Advances

Q3 **RISK FACTORS**

- Genetic heritability and shared environmental factors among twin pairs with autism
- Rare de novo and transmitted copy-number variation in autistic spectrum disorders
- Exome sequencing in sporadic autism spectrum disorders identifies severe de novo mutations
- Recurrence risk for autism spectrum disorders: A Baby Siblings Research Consortium study
- Multiple recurrent de novo CNVs, including duplications of the 7q11.23 Williams syndrome region, are strongly associated with autism

Q4 **TREATMENTS & INTERVENTIONS**

- A systematic review of medical treatments for children with autism spectrum disorders
- Intervention targeting development of socially synchronous engagement in toddlers with autism spectrum disorder: a randomized controlled trial
- Randomized, controlled trial of the LEAP model of early intervention for young children with autism spectrum disorders

Publications Selected for 2011 IACC Summary of Advances

Q5 **SERVICES**

- Post-high school service use among young adults with an autism spectrum disorder

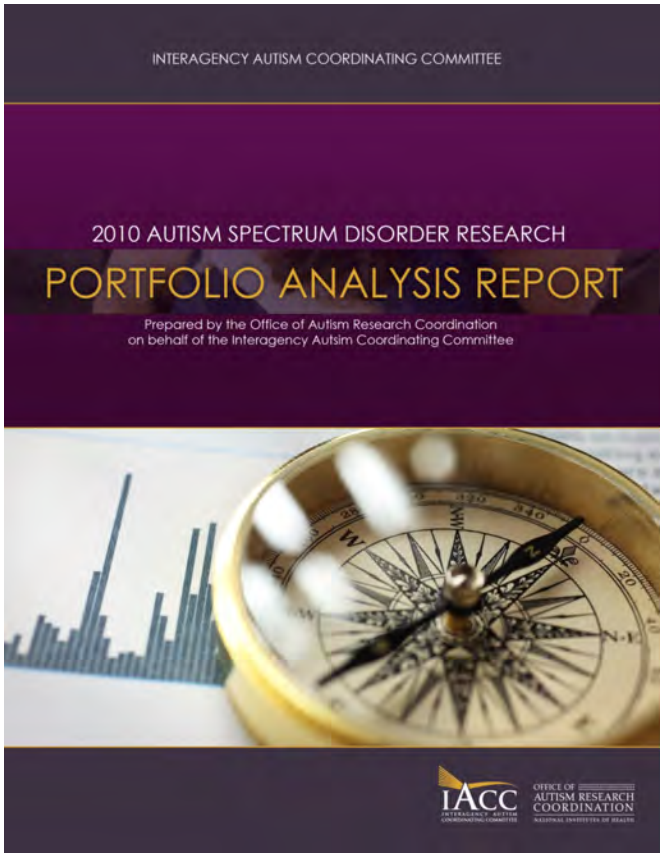
Q6 **LIFESPAN**

- Epidemiology of autism spectrum disorders in adults in the community in England
- Autism spectrum disorders in older adults: Toward defining a research agenda
- Emerging new practices in technology to support independent community access for people with intellectual and cognitive disabilities

Q7 **INFRASTRUCTURE & SURVEILLANCE**

- Trends in the prevalence of developmental disabilities in US children 1997-2008
- Prevalence of autism spectrum disorders in a total population sample

2010 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

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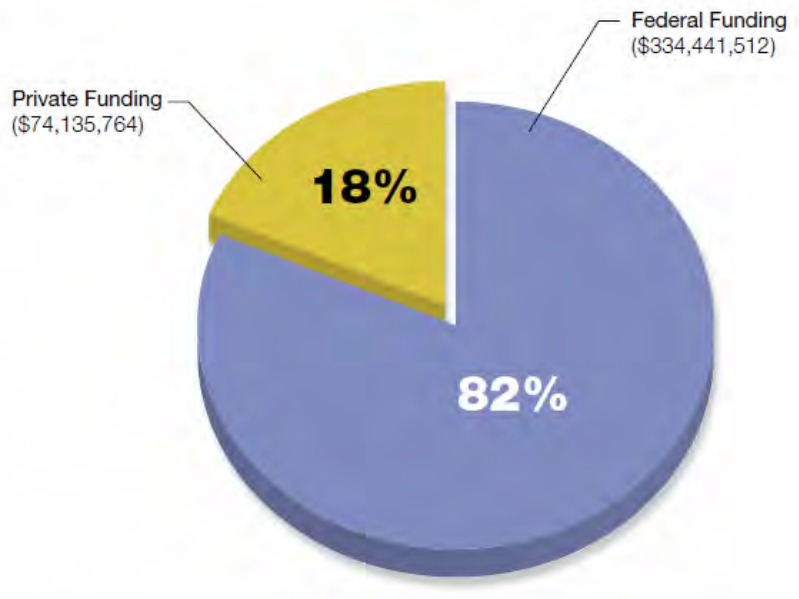
2010 Federal and Private Autism Funding

- **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
Simons Foundation (SF)	123	$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**

**Annual funding amounts for AHRQ, ED, and NSF are estimated.*
***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.* Private organizations are indicated in red text.

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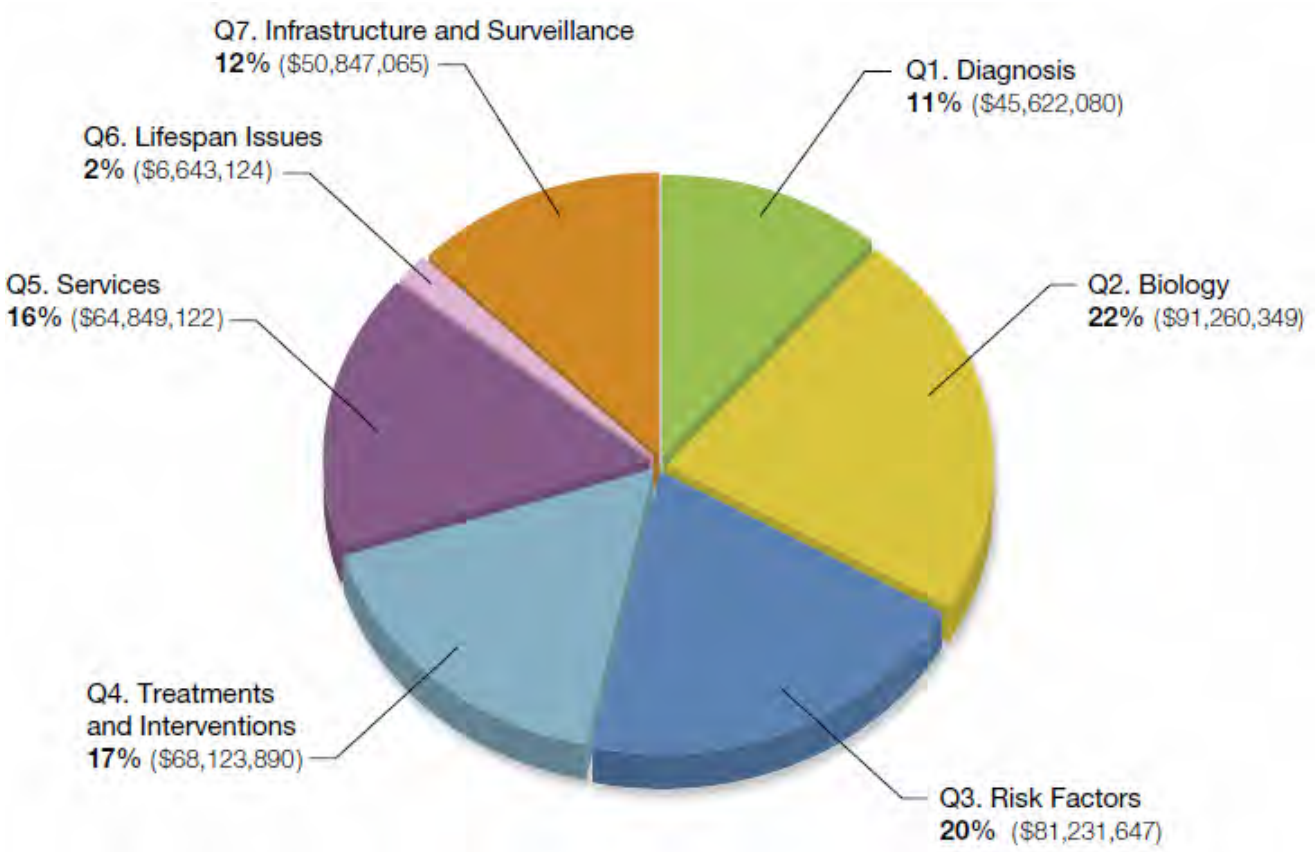
How Was 2010 Autism Funding (All Funders) Distributed Across the *IACC Strategic Plan* Questions?

Total funding = $408,577,276



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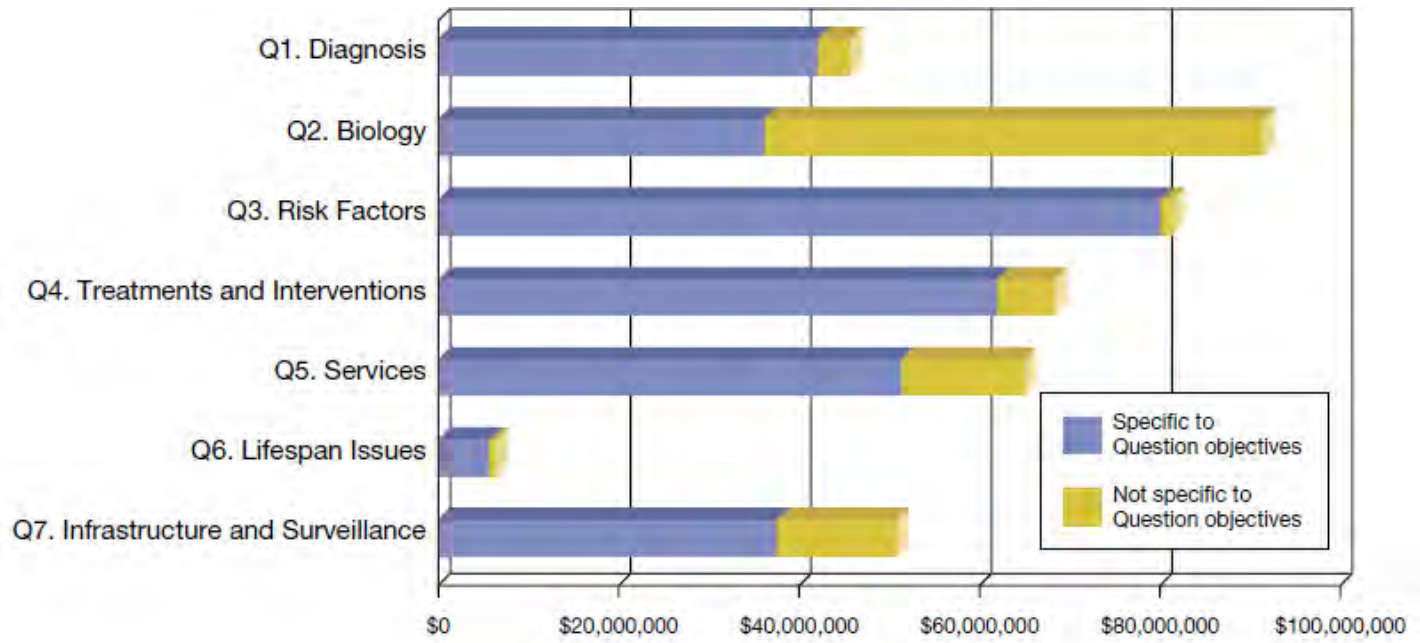
2010 ASD Funding: Alignment with *IACC Strategic Plan* Objectives



	Q1. Diagnosis	Q2. Biology	Q3. RiskFactors	Q4. Treatments and Interventions	Q5. Services	Q6. Lifespan Issues	Q7. Infrastructure and Surveillance
Specific	$41,978,518	$36,145,461	$79,919,197	$61,833,257	$51,412,385	$5,971,605	$37,593,356
Not specific	$3,643,562	$55,114,188	$1,312,450	$6,290,633	$13,436,737	$671,619	$13,253,709
% of funding for each Question	8%	60%	2%	9%	21%	10%	26%

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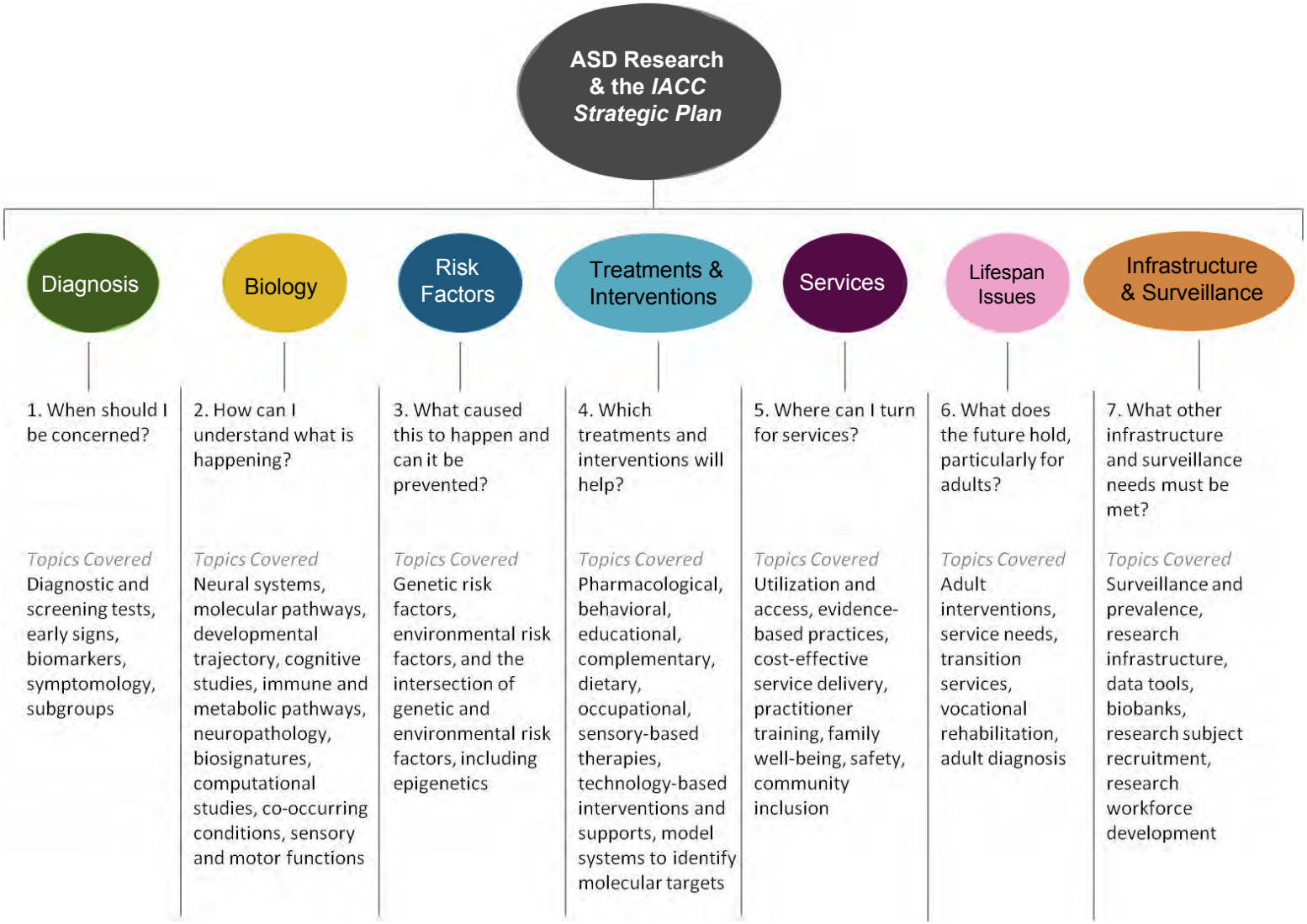
New in 2010: Subcategory Analysis

- Subcategories were developed for each of the seven questions of the *IACC Strategic Plan*
  - Provide a more detailed breakdown of research funding
  - Capture established and emerging research areas and areas of high public interest
  - Identify the types of research addressed by projects that do not correspond to specific objectives of the *Strategic Plan*
- Each project assigned to a single subcategory

Strategic Plan Structure and Portfolio Analysis Subcategories



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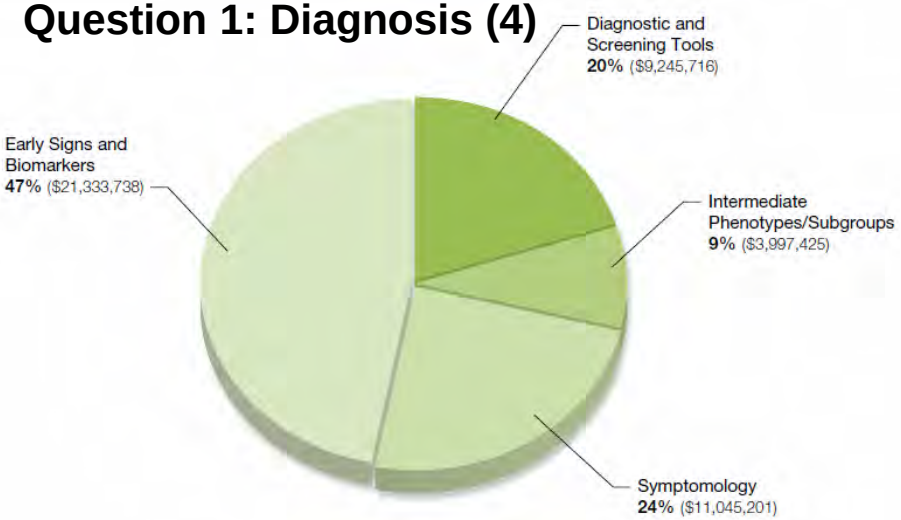
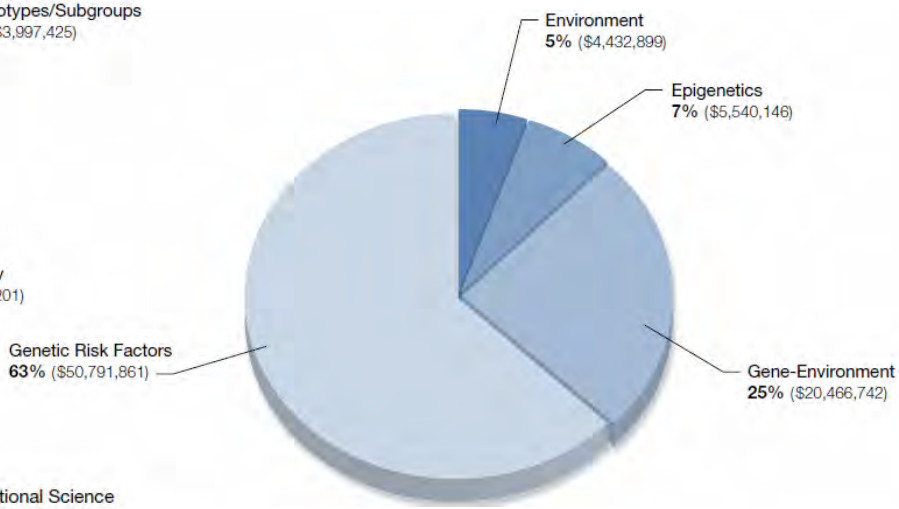
In 2010, How Much Funding Was Devoted to Each Subcategory?

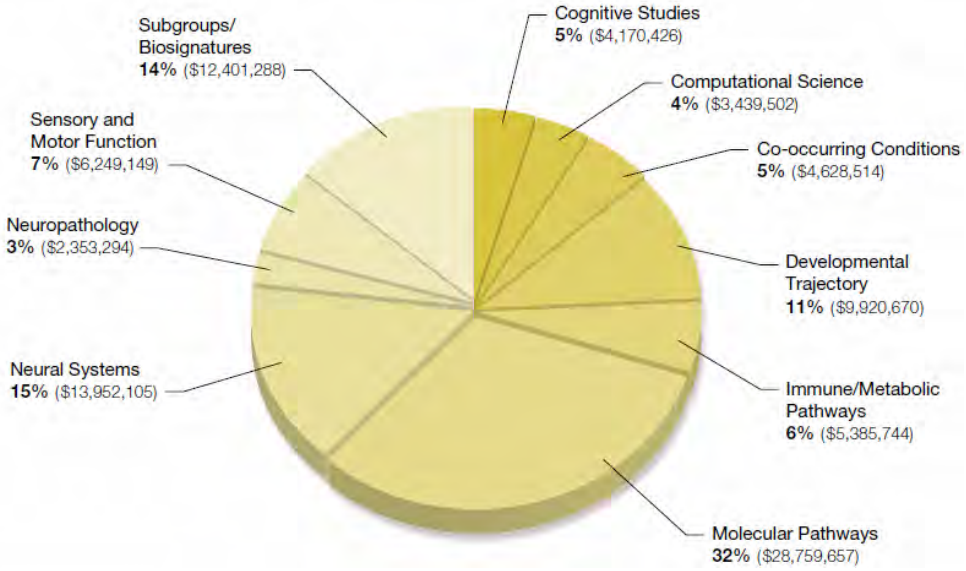
Question 1: Diagnosis (4)



Question 3: Risk Factors (4)

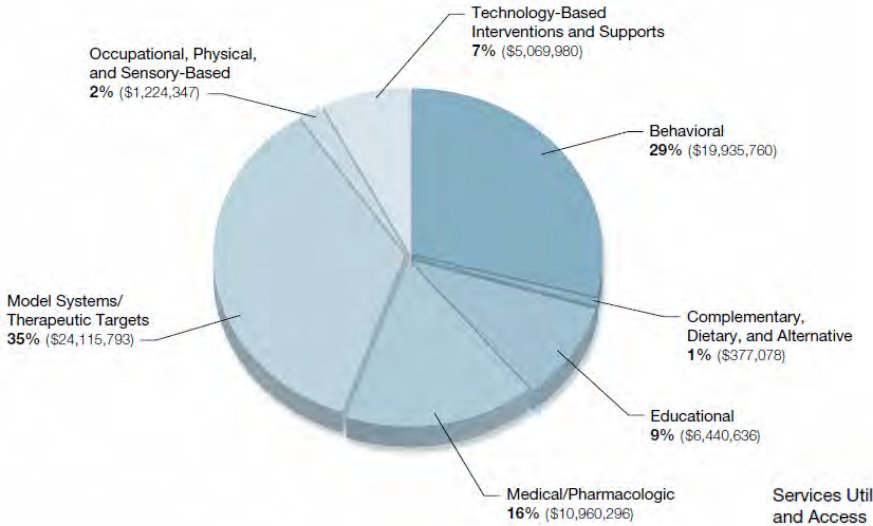


Question 2: Biology (10)

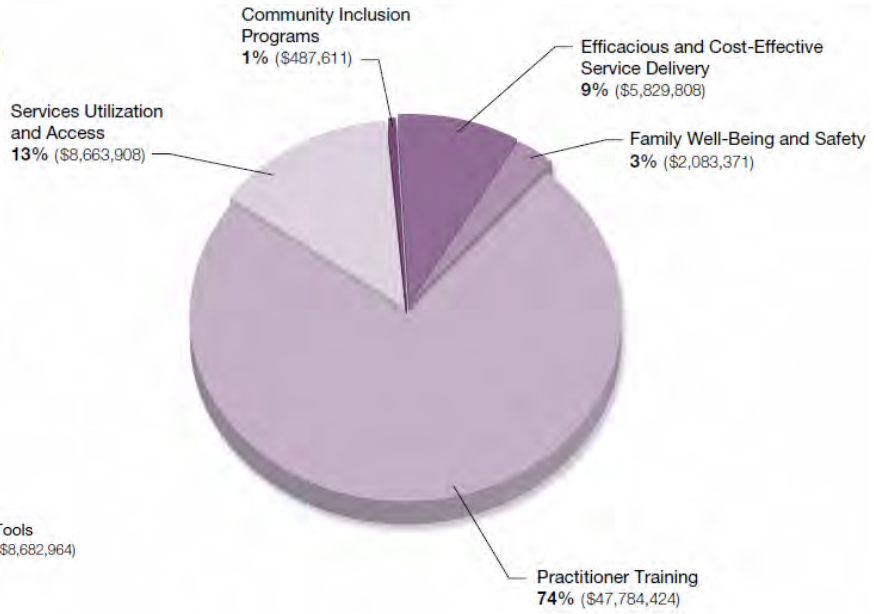


Subcategories by Funding

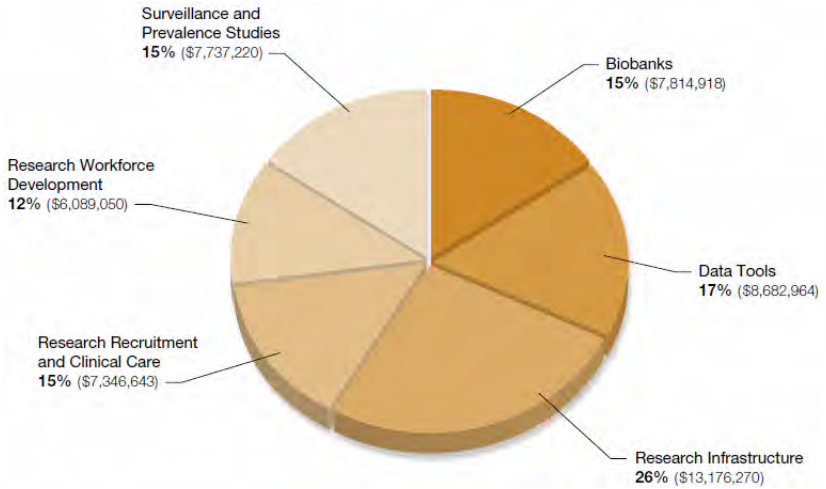
Question 4: Treatments and Interventions (7)



Question 5: Services (5)

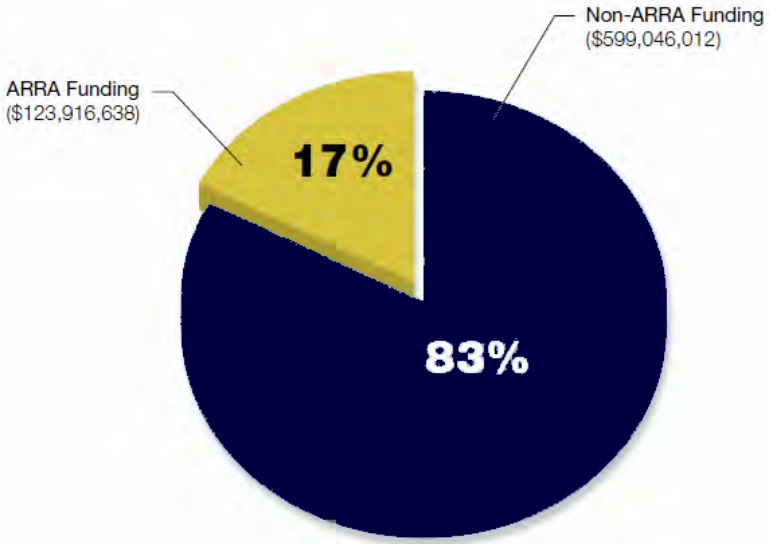


Question 7: Infrastructure and Surveillance (6)

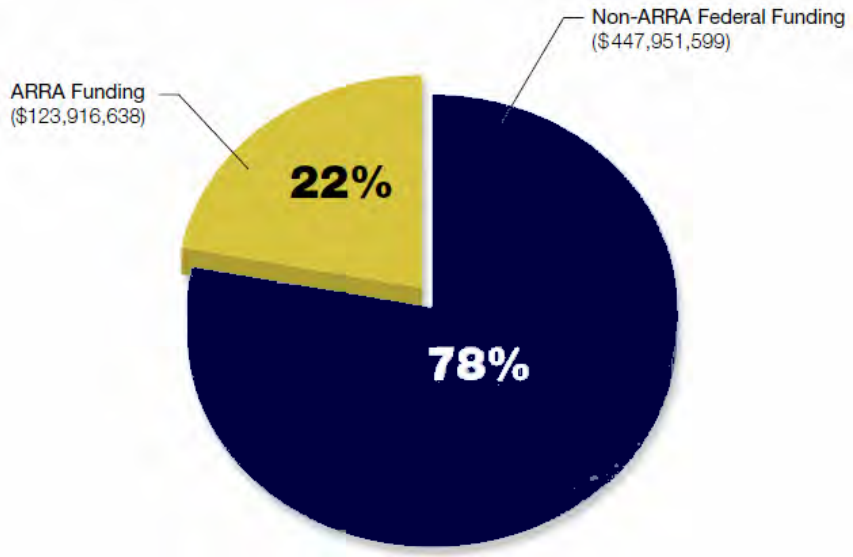


Impact of ARRA on ASD Research Funding in 2009 & 2010

Impact of ARRA on
Total ASD Research Funding
for 2009 & 2010
Total funding = $722,962,650



Impact of ARRA on
Federal ASD Research Funding
For 2009 & 2010
Total funding = $571,868,237



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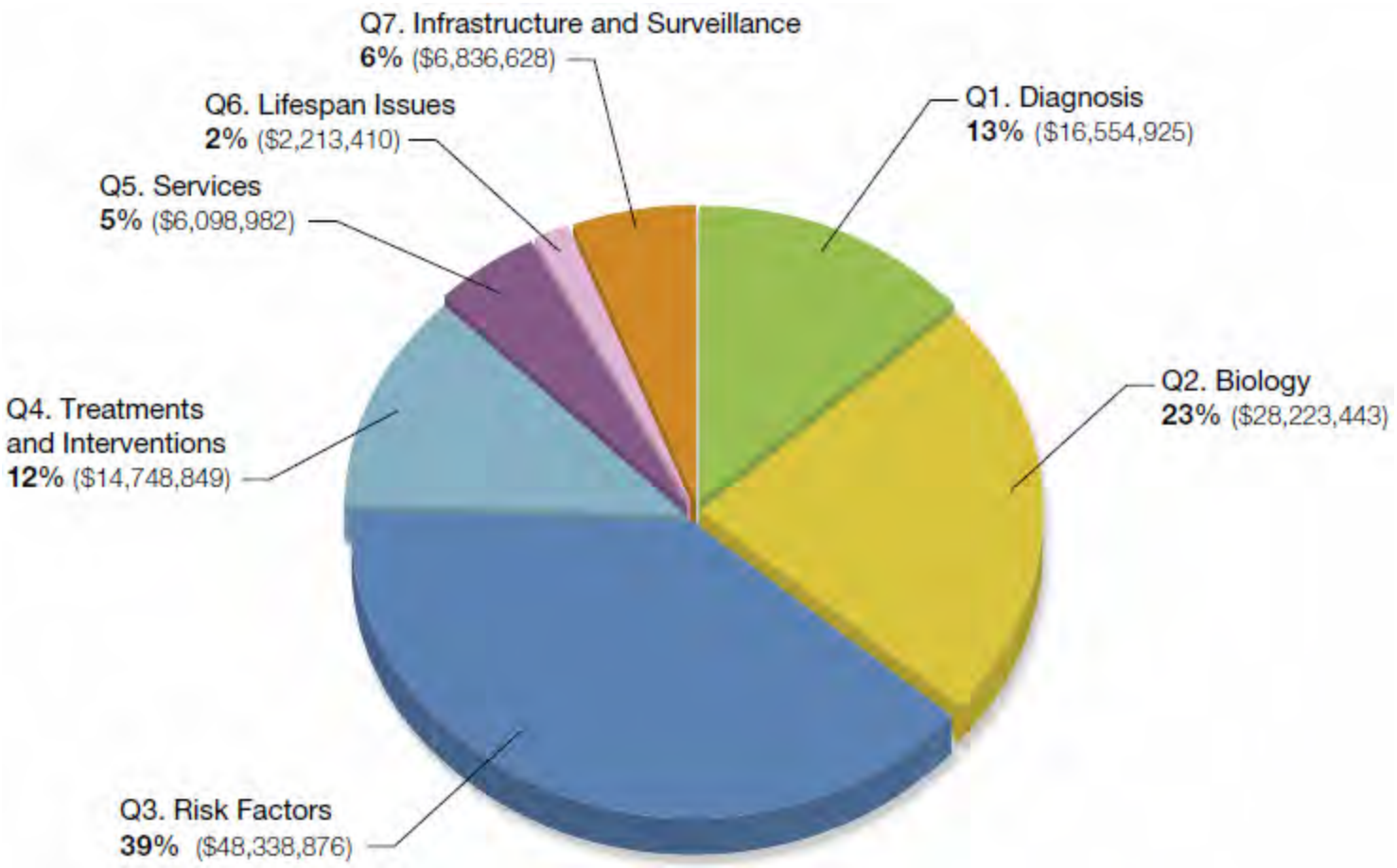
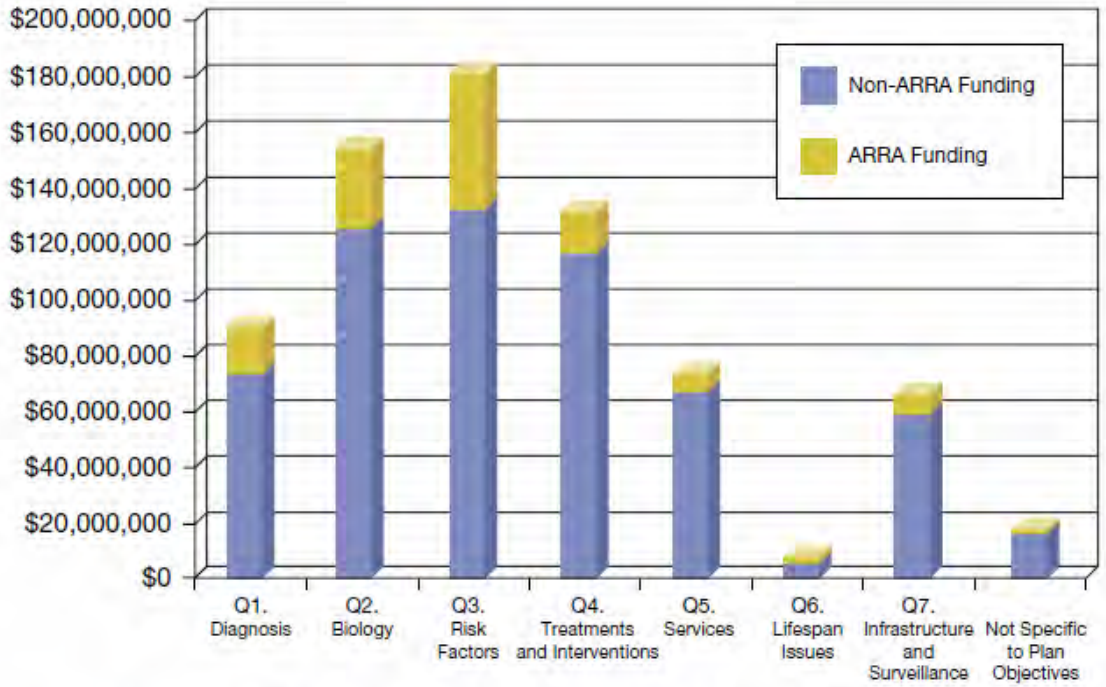
How was 2009 & 2010 ARRA ASD Research Funding Distributed Across the *IACC Strategic Plan* Questions?

Total ARRA funding = $123,916,638



Impact of 2009 & 2010 ARRA Funding on ASD Research: Alignment with the *IACC Strategic Plan*



	Q1. Diagnosis	Q2. Biology	Q3. Risk Factors	Q4. Treatments and Interventions	Q5. Services	Q6. Lifespan Issues	Q7. Infrastructure and Surveillance	Not Specific to Plan Objectives
Non-ARRA Funding	$73,761,097	$126,055,149	$132,830,821	$116,778,055	$67,398,190	$5,837,413	$59,589,569	$16,795,718
ARRA Funding	$16,554,925	$28,223,443	$48,338,876	$14,748,849	$6,098,982	$2,213,410	$6,836,628	$901,525
% of ARRA total funding per Question	18%	18%	27%	11%	8%	28%	10%	5%

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What Progress is Being Made on Achieving IACC Strategic Plan Objectives?

- In 2010 progress was underway on 83% of the 78 objectives in the 2011 IACC Strategic Plan.
- Since then two more objectives have been completed.
- Which objectives are not currently underway (i.e., no funding or projects to date)? 11 objectives spanning 6/7 Questions

1.S.C 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. *IACC Recommended Budget: $2,000,000 over 2 years.*

1.S.D Conduct at least two studies to understand the impact of early diagnosis on choice of intervention and outcomes by 2015. *IACC Recommended Budget: $6,000,000 over 5 years.*

Remaining Objectives – Cont'd

3.S.B 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. *IACC Recommended Budget: $3,500,000 over 3 years.*

4.S.E 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. *IACC Recommended Budget: $50,000.*

5.L.B 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. *IACC Recommended Budget: $16,700,000 over 5 years.*

6.L.D 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 on the ASD spectrum over age 21 by 2023. *IACC Recommended Budget: $4,000,000 over 5 years.*

Remaining Objectives – Cont'd

7.A 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 healthcare, education and social services by 2009. *IACC Recommended Budget: $520,000 over 1 year.*

7.F Create funding mechanisms that encourage rapid replication studies of novel or critical findings by 2011. *(No recommended budget assigned by the IACC.)*

7.G Develop a web-based tool which provides population estimates of ASD prevalence for states based on the most recent prevalence range and average identified by the ADDM Network by 2012. *IACC Budget Recommendations: $200,000 over 2 years.*

7.M 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. *IACC Recommended Budget: $75,000 over 5 years.*

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All IACC publications and more information about the IACC are available at: www.iacc.hhs.gov

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INTERAGENCY AUTISM COORDINATING COMMITTEE

OFFICE OF AUTISM RESEARCH COORDINATION
NATIONAL INSTITUTES OF HEALTH

Susan Daniels, Ph.D., Acting Director

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Nicole Jones, Senior Web Developer

Miguelina Perez, Management Analyst

Sarah Rhodes, Ph.D., Policy Analyst/Detailee, NIMH Intramural Program

Meeting of the IACC

IACC/OARC Autism Spectrum Disorder Research Portfolio Analysis Web Tool

Elizabeth M. Baden, Ph.D.
Policy Analyst, Office of Autism Research Coordination
IACC Full Committee Meeting – July 10, 2012

These slides do not reflect decisions of the IACC and are for discussion purposes only.

IACC/OARC ASD Research Portfolio Analysis Web Tool

- Online database
- Purpose: To provide funders, researchers and public stakeholders with detailed information about research projects and portfolios funded by government agencies and private organizations
- What it contains: Data from funded projects catalogued in the *2009* and *2010 IACC Portfolio Analysis Reports*
- Functionality:
  - 'Browse' by categories
    - Project, Funder, *Strategic Plan* Question, *Strategic Plan* Objective, Subcategory
  - 'Search' by keywords
    - e.g., "environment"
- Export data to Excel or PDF

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NATIONAL INSTITUTES OF HEALTH

IACC/OARC Autism Spectrum Disorder Research Portfolio Analysis Web Tool BETA

Fiscal Year: 2010

The *IACC/OARC Autism Spectrum Disorder Research Portfolio Analysis Web Tool* is an online companion database to the *2009* and *2010 Autism Spectrum Disorder Research Portfolio Analysis Reports*. The *Portfolio Analyses* are produced on behalf of the Interagency Autism Coordinating Committee (IACC) to better inform the IACC and interested stakeholders about the funding landscape and current directions for ASD research.

The IACC Portfolio Analysis Report
How to use the Web Tool

National Institutes of Health (545 projects)
Simons Foundation (123 projects)
Health Resources and Services Administration (82 projects)
Department of Education (139 projects)
Centers for Disease Control and Prevention (30 projects)
Autism Speaks (228 projects)
National Science Foundation (69 projects)
Department of Defense (58 projects)
Administration for Children and Families (1 projects)
Agency for Healthcare Research and Quality (4 projects)
Center for Autism and Related Disorders (31 projects)
Environmental Protection Agency (1 projects)
Autism Research Institute (15 projects)
Centers for Medicare & Medicaid Services (3 projects)
Autism Science Foundation (13 projects)
Organization for Autism Research (12 projects)

Search 2010 projects: To search, AND OR NOT may be used. Submit Clear

Browse by Project | Browse by Funder | Browse by Strategic Plan Question | Browse by Strategic Plan Objective | Browse by Subcategory

Export selected to: PDF EXCEL Download 2010 projects (EXCEL)

1,367 projects found Displaying 1 to 100. [First/Prev] 1, 2, 3, 4, 5, 6, 7, 8, 9, 10 [Next/Last]

Note: Initial Sort is by Strategic Plan Objective. Sorting by other columns is available by clicking on the desired column header. Secondary sort is always Strategic Plan Question.
Please note that the 2010 IACC Strategic Plan was used to analyze the 2009 data and the 2011 IACC Strategic Plan was used to analyze the 2010 data.

Export	Funder	Principal Investigator	Project Title	Funding	Strategic Plan Question	Strategic Plan Subcategory	Strategic Plan Objective	Objective Status Code	ARRA	Federal/Private	Institution	State/Country	Project Status
☐	Autism Speaks	Roark, Erian	Automated measurement of dialogue structure in autism	$0.00	Question 1:Diagnosis	Intermediate Phenotypes/Subgroups	Q1SA	●	No	Private	Oregon Health & Science University	Oregon	Ongoing
☐	Autism Speaks	Bahn, Sabine	Biomarkers and diagnostics for ASD	$149,600.00	Question 1:Diagnosis	Early Signs and Biomarkers	Q1SA	●	No	Private	Institute of Biotechnology	United Kingdom	New
☐	Center for Autism and Related Disorders	Dixon, Dennis	Psychometric evaluation of the autism symptom diagnostic scale	$8,975.00	Question 1:Diagnosis	Diagnostic and Screening Tools	Q1SA	●	No	Private	Center for Autism and Related Disorders (CARD)	California	Ongoing
☐	National Institutes of Health	Lord, Catherine	1/2 Development of a screening interview for research studies of ASD	$665,065.00	Question 1:Diagnosis	Diagnostic and Screening Tools	Q1SA	●	Yes	Federal	University of Michigan	Michigan	Ongoing
☐	National Institutes of Health	Bishop, Somer	2/2 Development of a screening interview for research studies of ASD	$372,239.00	Question 1:Diagnosis	Diagnostic and Screening Tools	Q1SA	●	Yes	Federal	Cincinnati Children's Hospital Medical Center	Ohio	Ongoing
☐	National Institutes of Health	Coster, Wendy	Computer adaptive testing of adaptive behavior of children and youth with autism	$284,375.00	Question 1:Diagnosis	Diagnostic and Screening Tools	Q1SA	●	Yes	Federal	Boston University	Massachusetts	Ongoing
☐	National Institutes of Health	Lord, Catherine	Development of a brief screener for research in autism spectrum disorders	$497,915.00	Question 1:Diagnosis	Diagnostic and Screening Tools	Q1SA	●	Yes	Federal	University of Michigan	Michigan	Ongoing
☐	National Institutes of Health	Fein, Deborah	Early detection of pervasive developmental disorders	$1,032,220.00	Question 1:Diagnosis	Diagnostic and Screening Tools	Q1SA	●	No	Federal	University of Connecticut	Connecticut	Ongoing

Details on Funders

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Browse by *Strategic Plan* Question

IACC INTERAGENCY AUTISM COORDINATING COMMITTEE

OFFICE OF AUTISM RESEARCH COORDINATION
NATIONAL INSTITUTES OF HEALTH

Projects Home » Strategic Plan Questions

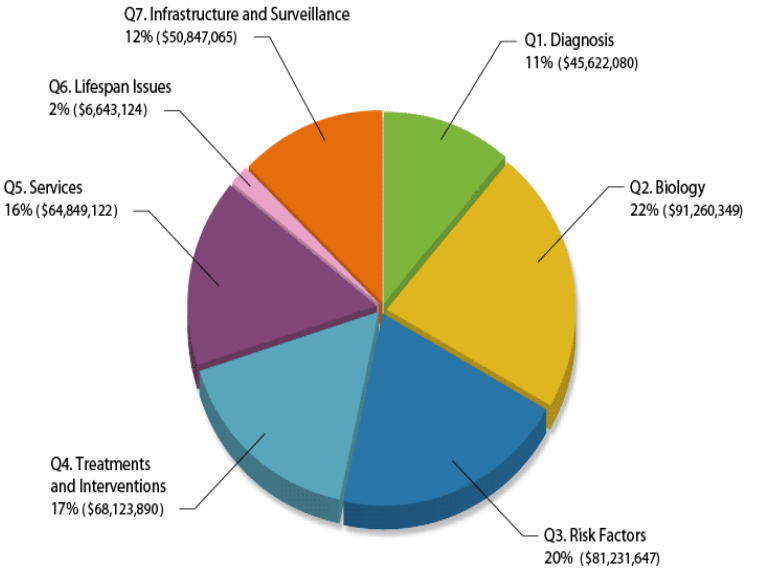
IACC/OARC Autism Spectrum Disorder Research Portfolio Analysis Web Tool[BETA]

Fiscal Year: 2010

Strategic Plan Question Listing

Browse by Project | Browse by Funder | Browse by Strategic Plan Question | Browse by Strategic Plan Objective | Browse by Subcategory

Strategic Plan Question	Number of Projects	Total Funding
Question 1: When Should I Be Concerned? (Diagnosis)	166	$45,622,079.14
Question 2: How Can I Understand What Is Happening? (Biology)	409	$91,260,348.78
Question 3: What Caused This To Happen And Can This Be Prevented? (Causes)	162	$81,231,647.06
Question 4: Which Treatments And Interventions Will Help? (Treatments)	277	$68,123,890.33
Question 5: Where Can I Turn For Services? (Services)	211	$64,849,122.00
Question 6: What Does the Future Hold, Particularly for Adults? (Lifespan)	34	$6,643,123.50
Question 7: What Other Infrastructure and Surveillance Needs Must Be Met? (Infrastructure)	108	$50,847,064.90
Total	1,367	$408,577,275.71



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Browse by Funder

IACC INTERAGENCY AUTISM COORDINATING COMMITTEE

OFFICE OF AUTISM RESEARCH COORDINATION
NATIONAL INSTITUTES OF HEALTH

Projects Home » Funders

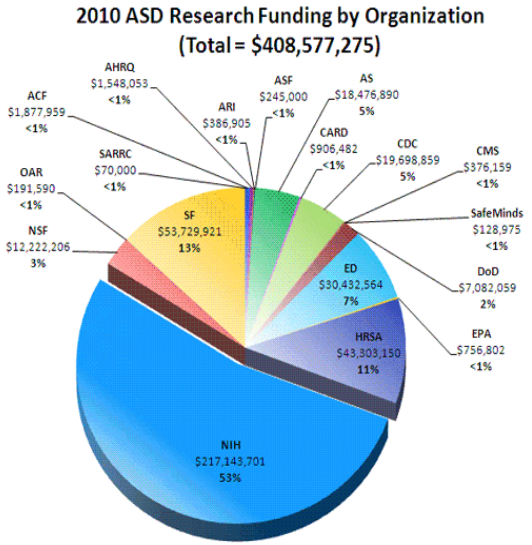
IACC/OARC Autism Spectrum Disorder Research Portfolio Analysis Web Tool[BETA]

Fiscal Year: 2010

Funder Listing

Browse by Project | Browse by Funder | Browse by Strategic Plan Question | Browse by Strategic Plan Objective | Browse by Subcategory

Funding Agency/Organization	Number of Projects	Total Funding
National Institutes of Health (NIH)	545	$217,143,701.00
Simons Foundation (SF)	123	$53,729,921.46
Health Resources and Services Administration (HRSA)	82	$43,303,150.00
Department of Education (ED)	139	$30,432,564.00
Centers for Disease Control and Prevention (CDC)	30	$19,698,859.00
Autism Speaks (AS)	228	$18,476,890.00
National Science Foundation (NSF)	69	$12,222,206.25
Department of Defense (DOD)	58	$7,082,059.00
Administration for Children and Families (ACF)	1	$1,877,959.00
Agency for Healthcare Research and Quality (AHRQ)	4	$1,548,053.00
Center for Autism and Related Disorders (CARD)	31	$906,482.00
Environmental Protection Agency (EPA)	1	$756,802.00
Autism Research Institute (ARI)	15	$386,905.00
Centers for Medicare & Medicaid Services (CMS)	3	$376,159.00
Autism Science Foundation (ASF)	13	$245,000.00
Organization for Autism Research (OAR)	12	$191,590.00
Coalition for SafeMinds (SAFEMINDS)	8	$128,975.00
Southwest Autism Research & Resource Center (SARRC)	5	$70,000.00
Total	1,367	$408,577,275.71



These slides do not reflect decisions of the IACC. They are for discussion purposes only.

IACC/OARC ASD Research Portfolio Analysis Web Tool

- Found within the IACC website:

  https://iacc.hhs.gov/apps/portfolio-analysis-web-tool/projects

- Acknowledgments – OARC Staff
  - Susan Daniels, Acting Director
  - Elizabeth Baden, Policy Analyst
  - Cyrus Davani, Scientific Program Analyst
  - Sara Dodson, AAAS Science & Technology Policy Fellow/Health Scientist
  - Nicole Jones, Web Developer
  - Miguelina Perez, Management Analyst
  - Sarah Rhodes, Policy Analyst/Detailee, NIMH Intramural Research Program

IACC/OARC ASD Research Publications Analysis Report: The Global Landscape of Autism Research July 2012

Pre-publication draft

Sara E. Dodson, PhD
Policy Analyst, OARC

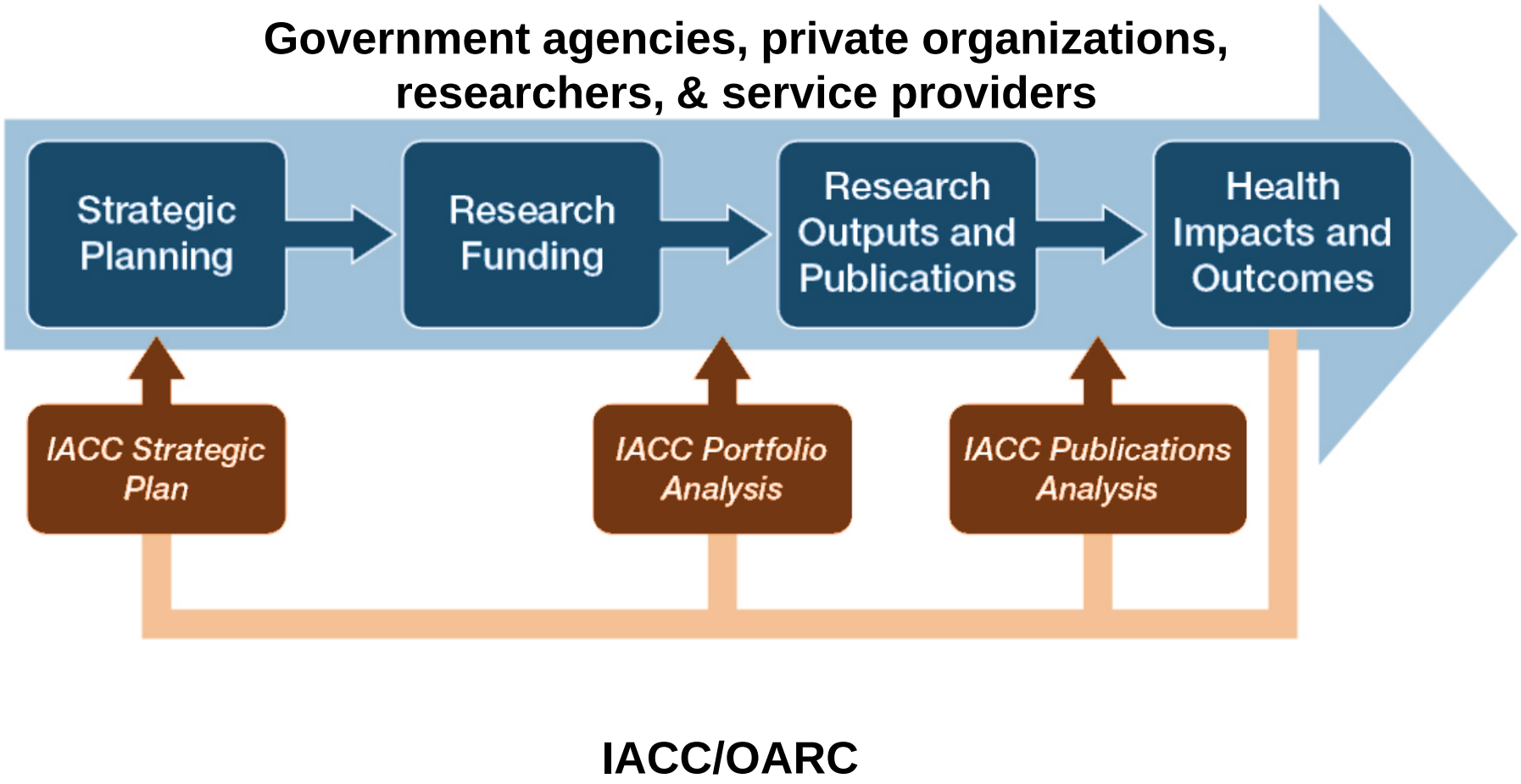
IACC Full Committee Meeting
July 10, 2012

PDF available on the IACC Website at:
http://iacc.hhs.gov/publications-analysis/july2012/index.shtml

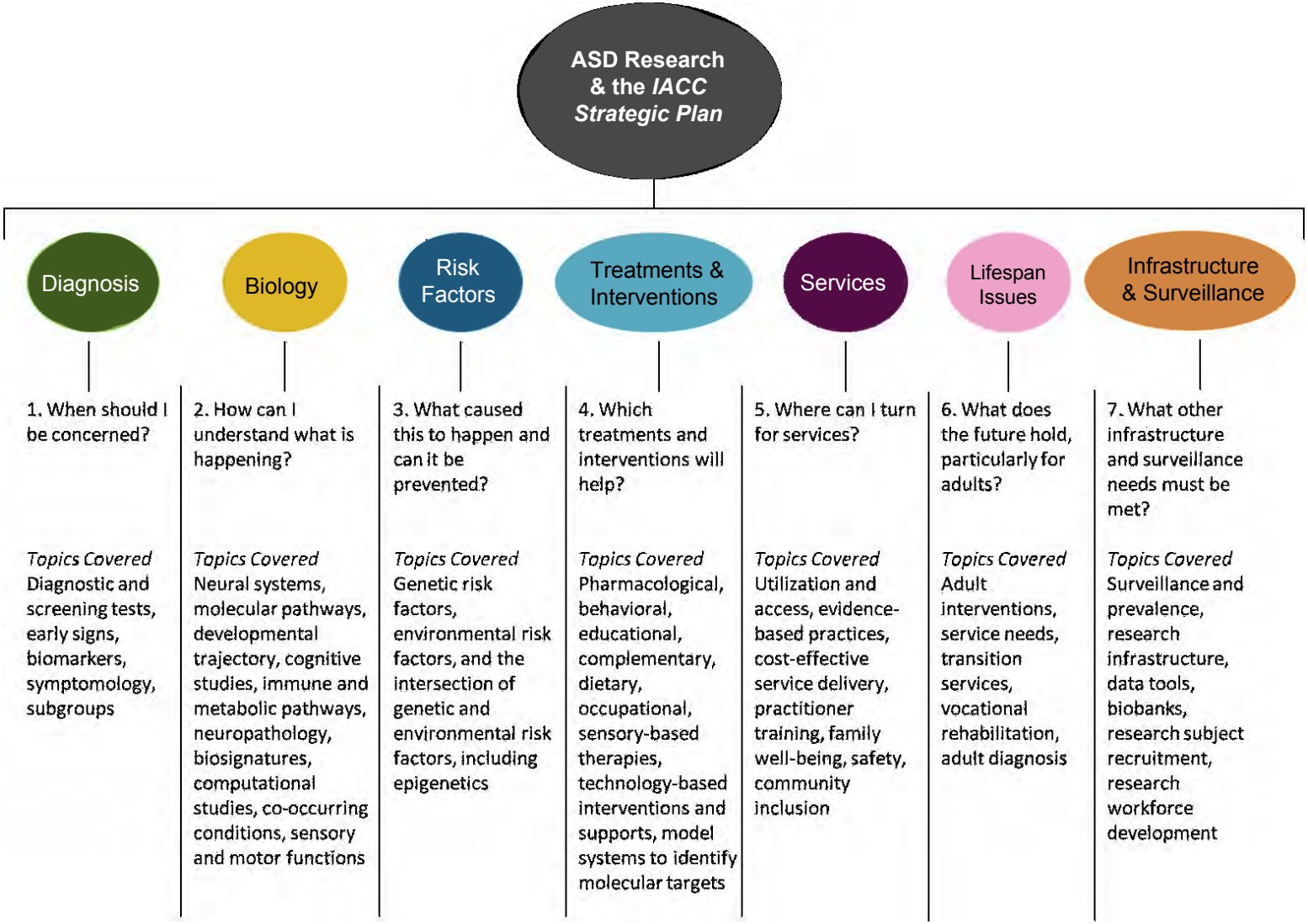
ASD Publications Analysis: Purpose and Approach

- Requested by the IACC to aid in monitoring outputs of ASD research efforts
- Utilized autism policy analysis expertise at OARC and scientific publication/data analysis expertise provided by Thomson Reuters, Inc.
- Helps describe the “state of the science” for autism research and how publications align with the *IACC Strategic Plan*
- Provides the IACC with an additional tool to identify key trends in research, opportunities, and knowledge gaps

How does the Publications Analysis fit in with other IACC/OARC activities?



The Publications Analysis helps map publications to the critical research areas in the IACC Strategic Plan



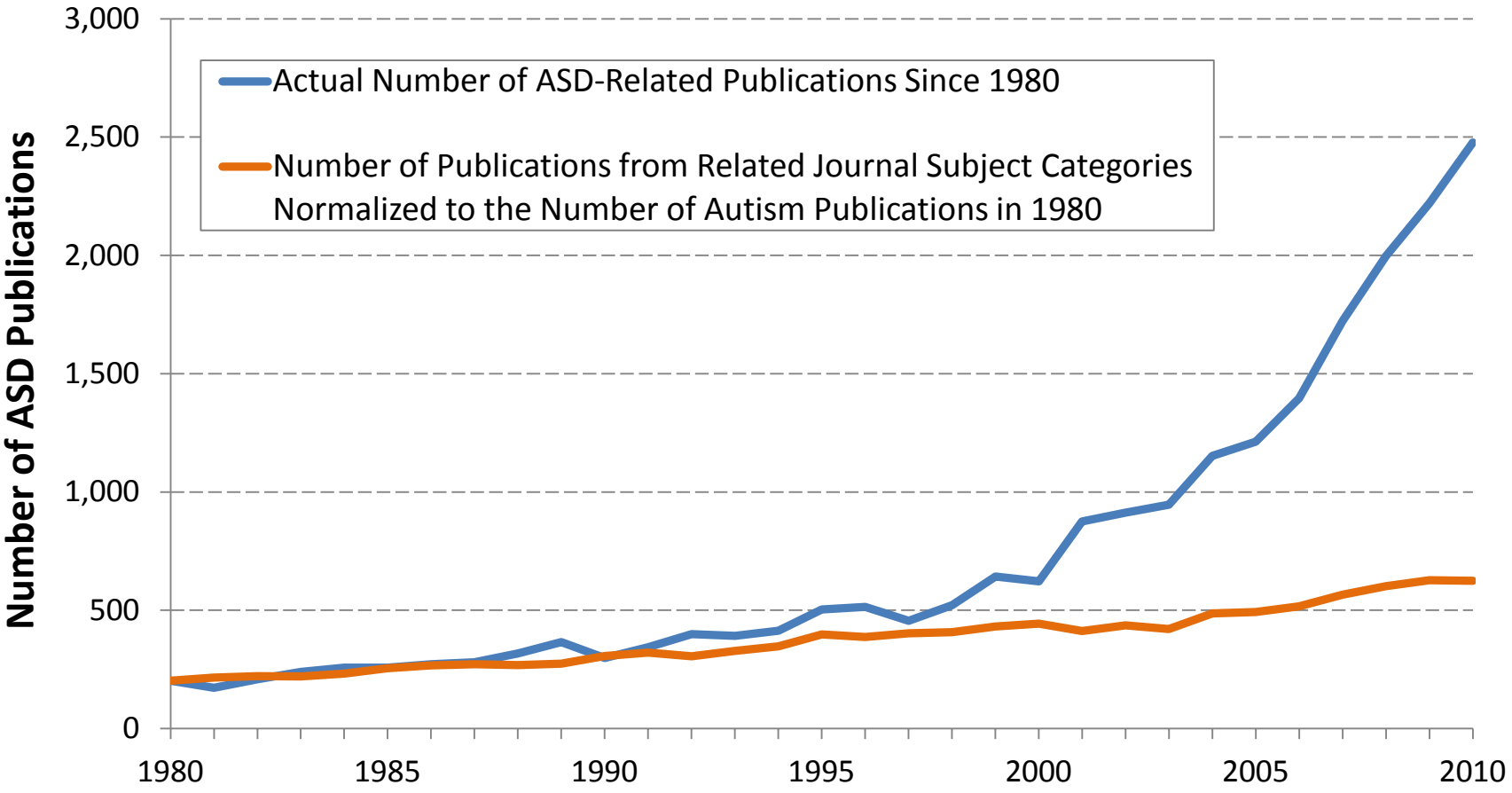
Main Questions Addressed in the *ASD Publications Analysis*

- How much has autism research grown?
- What autism research topics are being addressed?
- What is the impact of autism research publications?
- Who is funding autism research?
- Where is autism research being conducted?
- Is collaborative research increasing in the US and worldwide?

How much has autism research grown?

- An automated approach was used to identify articles published from 1980 to 2010 with the key words and terms, including:
  - autism, autistic, Asperger, or pervasive developmental disorder
- 25,000+ autism-relevant articles were published from 1980 to 2010

How much has autism research grown since 1980?



12-fold increase in annual publication rate since 1980

Sharp increase is evident around the year 2000

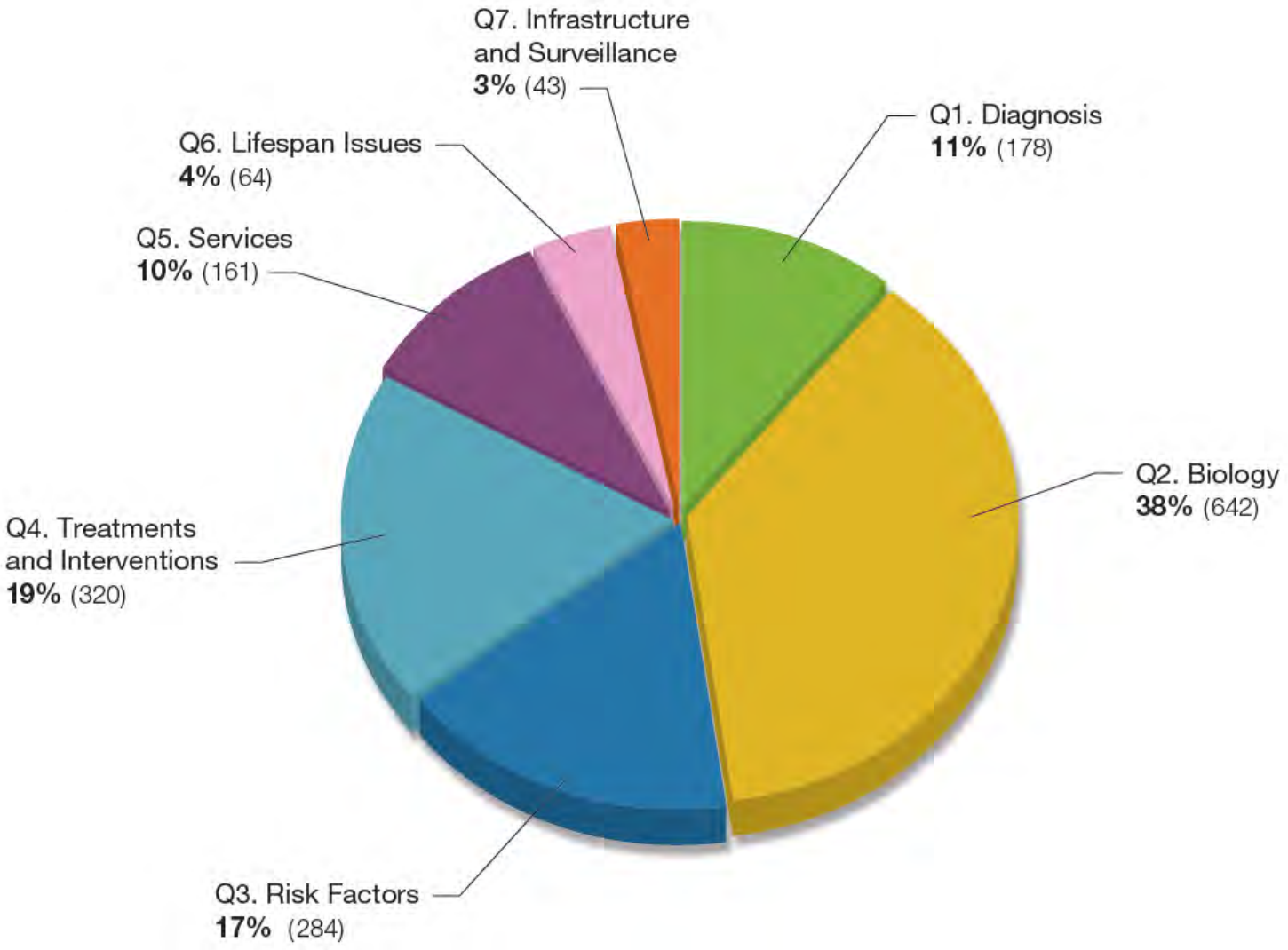
Summary: What did we learn?

- How much has autism research grown?
  - Dramatic growth since 2000 outpaces related research fields
  - More details are provided in the Report, including a discussion of driving factors that may be contributing to the overall growth of the field

What autism research topics have been addressed?

- OARC analysts manually categorized 2010 ASD-related publications
  - Each publication was assigned to one critical research area of the *IACC Strategic Plan*
- Customized algorithm was developed to classify publications from 1980 to 2009

How were 2010 research publications distributed across the seven Critical Question areas of the *IACC Strategic Plan?*



Summary: What did we learn?

- What autism research topics are being addressed?
  - Distribution of ASD publications across the *IACC Strategic Plan* is similar to that seen in the *IACC Portfolio Analysis*
  - More publications were observed in "basic" research areas than translational/applied research
  - Much more on autism research topics can be found in the Publications Analysis Report:
    - Growth curves by *Strategic Plan* Critical Question areas
    - In-depth analysis on *Risk Factors* and *Treatments and Interventions*

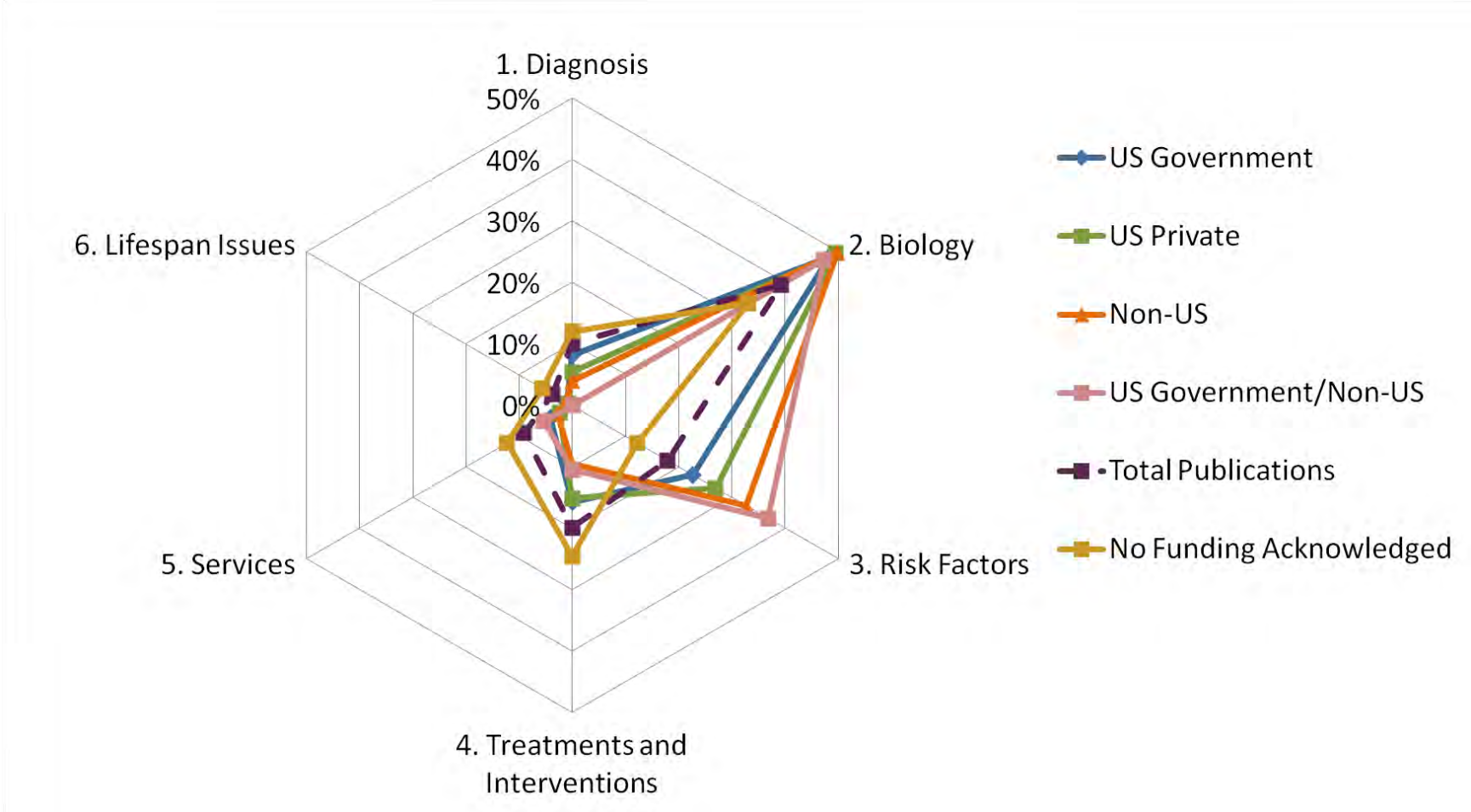
Who is funding research and what kinds of research were funded by different funder types?

- The ScienceWire database collects "Acknowledgment" paragraphs in publications and identifies funders who are cited for providing financial support
- Funders supporting 2010 ASD publications were identified and classified as:
  - US or non-US
  - Government or Private
- 36% of 2010 publications acknowledged a funding source, and more than 700 global funders of autism research were identified

Who were the top 15 funders acknowledged in 2010 ASD publications?

	Funding Organization	Country	Funder Type	Publications with acknowledgment
1	National Institutes of Health	US	Government	437
2	Autism Speaks	US	Private	119
3	The Medical Research Council	UK	Government	59
4	European Union	EU	Government	38
5	Wellcome Trust	UK	Private	36
6	The Canadian Institutes of Health Research	Canada	Government	35
7	Simons Foundation	US	Private	27
8	National Science Foundation	US	Government	26
9	Ministry of Education, Science, Sport and Culture	Japan	Government	25
10	Brain and Behavior Research Foundation/NARSAD	US	Private	24
11	Japan Society for the Promotion of Science	Japan	Government	18
12	German Research Foundation (DFG)	Germany	Government	17
13	Netherlands Organization for Scientific Research (NWO)	Netherlands	Government	15
14	Natural Sciences and Engineering Research Council	Canada	Government	14
15	National Institute for Health and Medical Research	France	Government	13

What kinds of research did different funder types support according to 2010 autism publications data?



Similar patterns of publication support observed from US Government, US Private, and non-US funders

Publications without funding acknowledgment are skewed toward *Treatments*, *Services*, and *Lifespan*

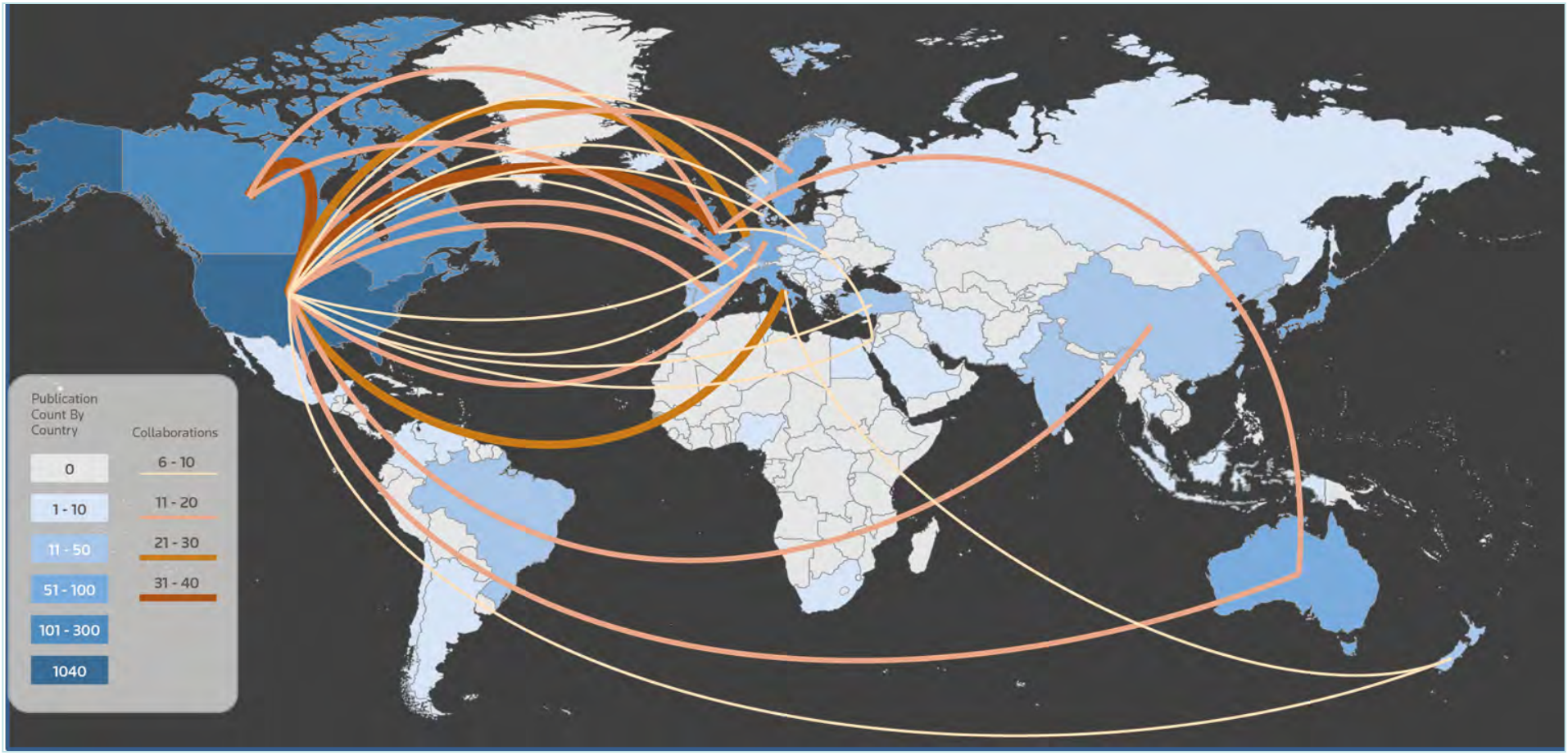
Summary: What did we learn?

- Who is funding autism research?
  - 2010 publications acknowledged more than 700 global funders, including many government and many private funders.
  - Non-US funders accounted for ~half of all acknowledgments.
  - Only 36% of autism publications acknowledged a funding source, and the acknowledgment rate was particularly low for *Treatments and Interventions*, *Services*, and *Lifespan Issues*.
  - Low rates of funding acknowledgment make it difficult for funders to track and report research progress.

Where is autism research being conducted and what is the extent of global collaboration?

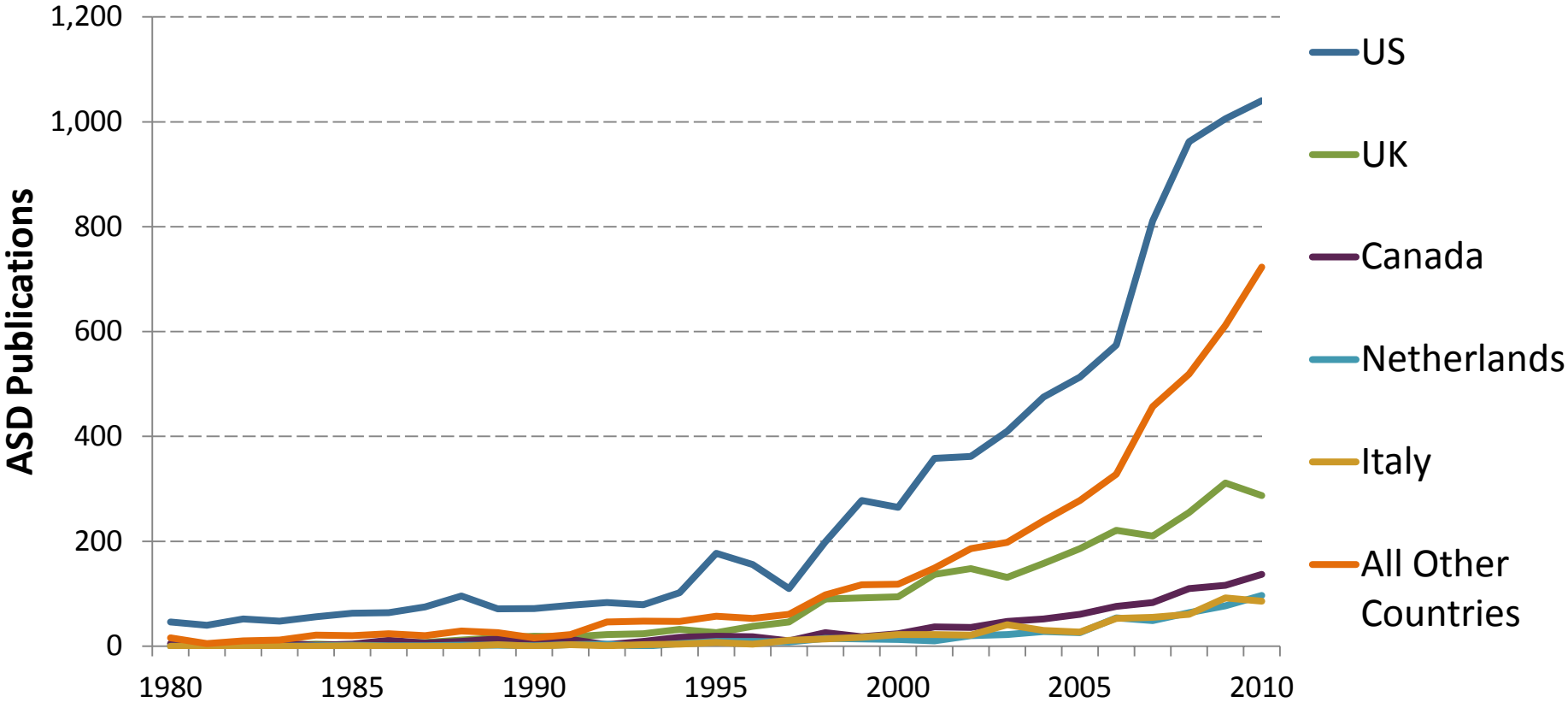
- Author addresses were used to identify which institutions and which countries have published ASD research
- Publications with author addresses from multiple countries and multiple institutions were assessed as a measure of “collaboration”
- Publication volume by country was analyzed from 1980 to 2010

Where was autism research conducted in 2010? Worldwide Publications and International Collaborations



ASD research was published by authors in over 50 countries and collaboration is most extensive between researchers in North America and Western Europe

Global Growth in Autism Publications from 1980 to 2010

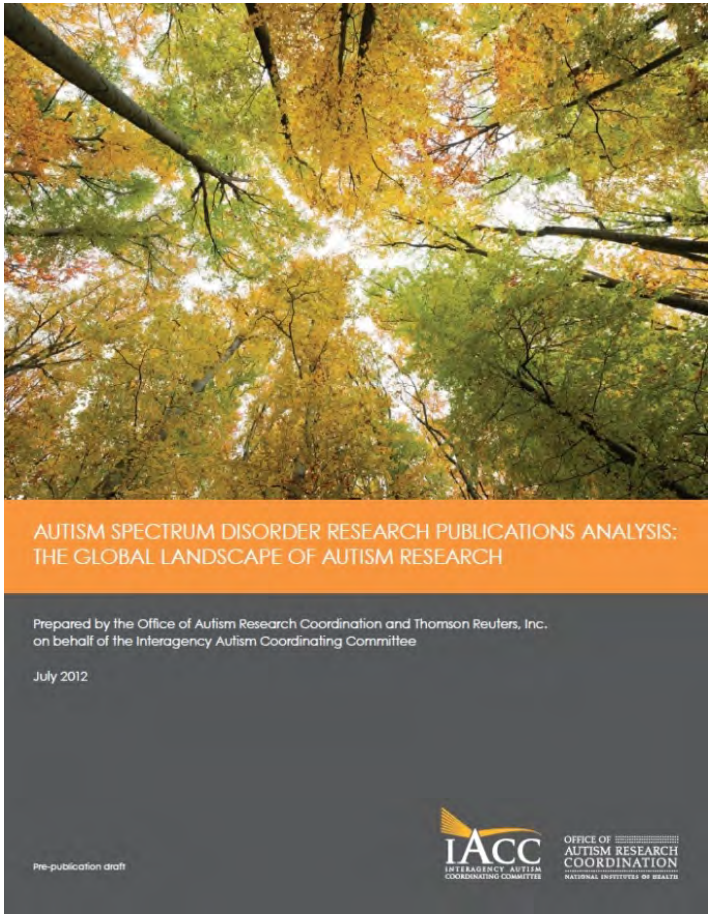


The US accounts for the largest number of ASD publications each year

"All Other Countries" = China, Taiwan, South Korea, India, Brazil, and Poland

Summary: What did we learn?

- Where is autism research being conducted and what is the extent of collaboration in the field?
  - In 2010, autism research was published by authors in over 50 countries and more than 1,800 research institutions worldwide.
  - The US is the largest producer of ASD publications.
  - A recent sharp increase in publications was observed from China, South Korea, Taiwan, India, Brazil, and Poland.
  - Much more can be found in the Report, including analysis of collaborations between countries and institutions.



Find the full pre-publication draft on the IACC website at: http://iacc.hhs.gov/publications-analysis/july2012/index.shtml

Final draft and extended Web appendices will be posted soon.

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Acknowledgments

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Nicole Jones
Miguelina Perez
Cyrus Davani
Joshua Schnell, Ph.D.
Duane Williams, Ph.D.
Yvette Seger, Ph.D.
Brian Lawton
Marie-Cafone Moss

Meeting of the IACC

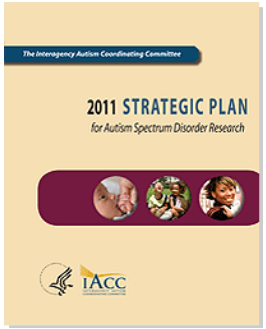
IACC Business

Thomas R. Insel, M.D.
Director, National Institute of Mental Health
Acting Director, National Center for Advancing Translational Sciences
Chair, IACC
IACC Full Committee Meeting – July 10, 2012

These slides do not reflect decisions of the IACC and are for discussion purposes only.

Responsibilities of the IACC

- Develop and update annually a summary of advances in ASD research
- Monitor Federal activities with respect to ASD
- Make recommendations to the HHS Secretary regarding research or public participation
- Develop and annually update and submit to Congress a strategic plan for ASD research
- Meet at least twice/year



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IACC Subcommittees

Services

Policy (access, housing, employment), Safety, Social inclusion, Health Disparities, Costs, Implications of ACA, etc.

Science

Research (biomedical, behavioral, services), Update of Research Strategic Plan, Collaborations, Biobanks, Registries, etc.

Subcommittee Process:

- Co-chairs (federal and non-federal)
- Members limited to IACC members
- All meetings public
- Reports/recommendations/actions subject to full IACC approval

Decisions for today

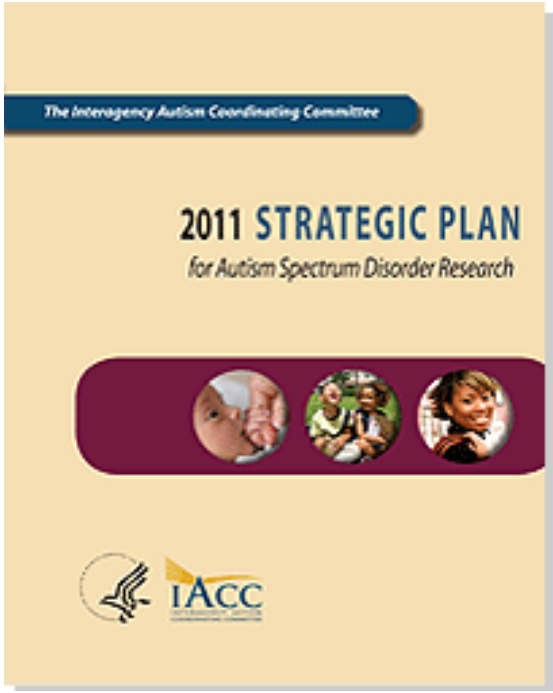
- Are these the right subcommittees?
- Which subcommittee will you serve on?
- Who will volunteer as co-chairs?
- How soon can we meet?

Strategic Plan Update

- Last plan January 2011
- Update due by December
  - 2012

What kind of update?

What process?



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Meeting of the IACC

Afternoon Agenda – Cont'd

4:30 **Public Comments Discussion Period**

5:00 **Closing Comments and Adjournment**

Meeting of the IACC

Closing Comments and Adjournment

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