

Meeting of the Interagency Autism Coordinating Committee

January 18, 2011

The Neuroscience Center
6001 Executive Boulevard
Conference Rooms C and D
Rockville, MD 20852

Conference Call Access:

Phone: (888) 577-8995

Access Code: 1991506

Meeting of the IACC

Morning Agenda

10:00 Call to Order and Opening Remarks

Thomas Insel, M.D., Chair, IACC

10:10 Review and Approval of December 14, 2010
Minutes

10:15 Round Robin IACC Member Updates

Geri Dawson, Ph.D., Lee Grossman, Walter Koroshetz,
M.D., Alison Singer M.B.A

10:30 Update on the Affordable Care Act and Health
Insurance Coverage

Cheryl Ulmer, Stuart Spielman, Esq., Jeffrey Sell, Esq.

11:30 Strategic Plan Update – Discussion and Votes

12:30 Lunch

IACC Update

January 2011

Thomas Insel, M.D.

Director, National Institute of Mental Health and Chair, IACC
IACC Full Committee Meeting - January 18, 2011

How can I understand what is happening?



N = 277
ASD/189 Con
AB to 45kDA
9.7% Aut vs
3.6% Con
Correl w lower
fcn/cog

Autoantibodies to cerebellum in children with autism associate with behavior

Paula Coinesa,b, Lori Haapanena,b, Robert Boyee,a,b, Paul Duncatisona,b, Daniel Braunschweiga,b, Lora Deiwichec,d, Robin Hansenb,d,c, Irva Hertz-Picciottob,c,d, Paul Ashwoodb,f, Judy Van de Watera,b,*

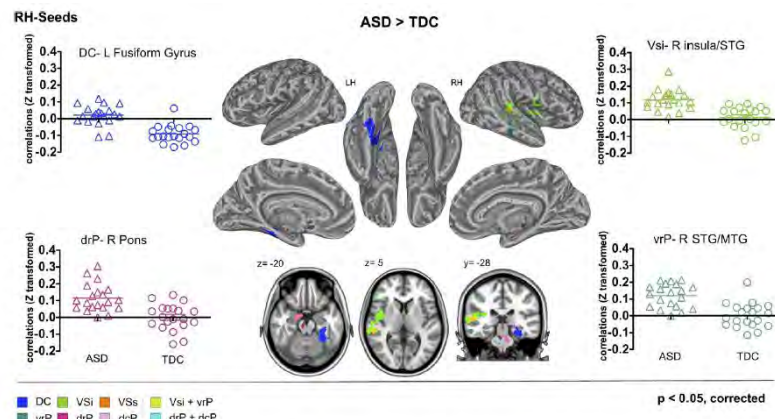
aDivision of Rheumatology, Allergy and Clinical Immunology. University of at Davis, Davis CA United States
bM.I.N.D. Institute, University of California at Davis, Davis, CA United States
cDepartment of Public Health Sciences, University of California at Davis, Davis, CA United States
dChildren's Center for Environment Health. University of California at Davis Davis, CA, United States

Aberrant Striatal Functional Connectivity in Children with Autism

Adriana Di Martino, Clare Kelly, Rebecca Grzadzinski, Xi-Nia Maria Angeles Mairena, Catherine Lord, F. Xavier Castellana

Biological Psychiatry 2011

N = 20 ASD vs 20 Con
Age = 7.6 – 13.5 yrs
Seeds in striatum



What caused this to happen and can it be prevented?

Polybrominated diphenyl ethers in relation to autism and developmental delay: A case-control study

N = 100

cases

11 PBDE

congeners

GCMS

Environmental Health 2011, 10:1 doi:10.1186/1476-069X-10-1

Irva Hertz-Picciotto (ihp@ucdavis.edu)

Ake Bergman (Ake.Bergman@mk.su.se)

Britta Fangstrom (britta.fangstrom@vinnova.se)

Melissa B Rose (mbrose@ucdavis.edu)

Paula Krakowiak (pkrakowiak@ucdavis.edu)

Isaac N Pessah (inpessah@ucdavis.edu)

Robin L Hansen (robin.hansen@ucdmc.ucdavis.edu)

Deborah H Bennett (dhbennett@ucdavis.edu)

Residential Proximity to Freeways and Autism in the CHARGE Study

Heather E. Volk, Irva Hertz-Picciotto, Lora Delwiche,
Fred Lurmann, and Rob McConnell

doi: 10.1289/ehp.1002835 (available at <http://dx.doi.org/>)
Online 16 December 2010



N = 304 ASD;
259 CON
3rd Trimester
< 309m of
freeway
OR = 2.22

What caused this to happen and can it be prevented?

Closely Spaced Pregnancies Are Associated With Increased Odds of Autism in California Sibling Births



WHAT'S KNOWN ON THIS SUBJECT: Autism has been associated with pregnancy and birth complications that may indicate a suboptimal prenatal environment. Although the interpregnancy interval (IPI) may affect the prenatal environment, the association between the IPI and risk for autism is not known.

AUTHORS: Keely Cheslack-Postava, PhD, MSPH,^a Kayuet Liu, DPhil,^b and Peter S. Bearman, PhD^b

^aRobert Wood Johnson Foundation Health and Society Scholars, Columbia University, New York, New York; and ^bPaul F. Lazarsfeld Center for the Social Sciences, Columbia University, New York, New York

N = 662, 730 2nd births; IPI < 12 mos vs IPI > 36 mos risk for ASD OR = 3.39

Neonatal Jaundice, Autism, and Other Disorders of Psychological Development



WHAT'S KNOWN ON THIS SUBJECT: Little and inconclusive evidence has been published regarding the association between neonatal jaundice and autistic disorders.

AUTHORS: Rikke Damkjær Maimburg, MPH, PhD,^{a,b} Bodil Hammer Bech, MD, PhD,^a Michael Væth, PhD,^c Bjarne Møller-Madsen, MD, DMSci,^d and Jørn Olsen, MD, PhD^{a,e}

N = 733,826 Danish births, HR = 1.67, higher in multiparous and winter births

Which treatments and interventions will help?

THE JOURNAL OF CHILD
PSYCHOLOGY AND PSYCHIATRY



Journal of Child Psychology and Psychiatry 52:1 (2011), pp 13-21

doi:10.1111/j.1469-7610.2010.02288.x

Intervention targeting development of socially synchronous engagement in toddlers with autism Spectrum disorder: a randomized controlled trial

Rebecca J. Landa,¹ Katherine C. Holman,² Allison H. O'Neill,³ and Elizabeth A. Stuart⁴

¹Kennedy Krieger Institute, Center for Autism and Related Disorders, Johns Hopkins University School of Medicine, Department of Psychiatry and Behavioral Sciences, Baltimore, MD, USA; ²Towson University, Department of Special Education, Towson, MD, USA; ³University of Maryland School of Public Health, Department of Epidemiology and Biostatistics, College Park, MD, USA; ⁴Johns Hopkins Bloomberg School of Public Health, Departments of Mental Health and Biostatistics, Baltimore, MD, USA

N = 50 ASD toddlers 21 – 33 months; 6 month Rx of Interpersonal Synchrony; doubling of social engagement (17% - 42%), generalization



HHS Secretary's Report to Congress

Report to Congress on Activities Related to Autism Spectrum Disorders and Other Developmental Disabilities Under the Combating Autism Act of 2006 (FY 2006-FY 2009)

**Prepared by the Office of Autism Research Coordination
National Institutes of Health
Department of Health and Human Services**

Will be posted to the IACC Website Reports Section Soon:
<http://iacc.hhs.gov/reports/>

Presentation to the Interagency Autism Coordinating Committee Meeting (IACC) on

The Essential Health Benefits Study

Cheryl Ulmer, Study Director
January 18, 2011



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OF THE NATIONAL ACADEMIES

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The Institute of Medicine asks and answers the nation's most pressing questions about health and health care.

The IOM is an independent, nonprofit organization that works outside of government to provide unbiased and authoritative advice to decision makers and the public.

Established in 1970, the IOM is the health arm of the National Academy of Sciences, which was chartered under President Abraham Lincoln in 1863.

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The IOM serves as adviser to the nation to improve health.

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- Evidence-based recommendations
- Committees composed to avoid conflicts of interest
- Neutral venue for open dialogue and discussion
- Honorific organization



IOM Membership

- More than 1,800 members and foreign associates
- 65 members elected each year
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The IOM's Unique Study Process



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The Essential Health Benefits Study

Section 1302 of the Affordable Care Act charges the Secretary of HHS to define an essential health benefits package offered by qualified health plans in the health insurance exchanges.

The Secretary has asked the IOM to help guide that process, not by specifying the particular benefits, but by giving some guiding policy principles, criteria and methods for defining and eventually updating the essential benefits package.



Steps to date

- Formed a committee
- Asked for public response on 10 questions
- Held the first of 4 committee meetings
- Audio files from the public sessions will be posted on our website:

<http://iom.edu/Activities/HealthServices/EssentialHealthBenefits.aspx>

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Elements of 1302: Categories of Care

- Ambulatory patient services
- Emergency services
- Hospitalization
- Maternity and newborn care
- Mental health and substance abuse disorder services, including behavioral health treatment
- Prescription drugs
- Rehabilitative and habilitative services and devices
- Laboratory services
- Preventive and wellness services and chronic disease management
- Pediatric services, including oral and vision care



Other Elements of Section 1302

Typical employer plan

Implications of inclusion or not of state mandates

Required elements for consideration:

-nondiscrimination based on age, disability, or expected length of life



Some Issues raised in public session

- Generosity of coverage vs. affordability
- The specificity of the essential benefit package at the federal level vs. flexibility in states and among insurers to tailor coverage policies
- Define or not define medical necessity, and define medical vs. non-medical services
- How to set priorities on what is considered essential
- What kind of safeguards should be established at national and/or state levels to monitor coverage decisions, reimbursement rates, or benefit design



10 Questions on Website:

1. What is your interpretation of the word “essential” in the context of an essential benefit package?
2. How is medical necessity defined and then applied by insurers in coverage determinations? What are the advantages/disadvantages of current definitions and approaches?
3. What criteria and methods, besides medical necessity, are currently used by insurers to determine which benefits will be covered? What are the advantages/disadvantages of these current criteria and methods?
4. What principles, criteria, and process(es) might the Secretary of HHS use to determine whether the details of each benefit package offered will meet the requirements specified in the Affordable Care Act?
5. What type of limits on specific or total benefits, if any, could be allowable in packages given statutory restrictions on lifetime and annual benefit limits? What principles and criteria could/should be applied to assess the advantages and disadvantages of proposed limits?
6. How could an “appropriate balance” among the ten categories of essential care be determined so that benefit packages are not unduly weighted to certain categories?
7. How could it be determined that essential benefits are “not subject to denial to individuals against their wishes” on the basis of age, expected length of life, present or predicted disability, degree of medical dependency or quality of life? Are there other factors that should be determined?
8. How could it be determined that the essential health benefits take into account the health care needs of diverse segments of the population, including women, children, persons with disabilities, and other groups?
9. By what criteria and method(s) should the Secretary evaluate state mandates for inclusion in a national essential benefit package? What are the cost and coverage implications of including all current state mandates in requirements for a national essential benefit package?
10. What criteria and method(s) should HHS use in updating the essential package? How should these criteria be applied? How might these criteria and method(s) be tailored to assess whether: (1) enrollees are facing difficulty in accessing needed services for reasons of cost or coverage, (2) advances in medical evidence or scientific advancement are being covered, (3) changes in public priorities identified through public input and/or policy changes at the state or national level?





Private Health Insurance Coverage for Autism Spectrum Disorders

Presented to the
Interagency Autism Coordinating Committee
January 18, 2011
by
Stuart Spielman
Senior Policy Advisor and Counsel
Autism Speaks

Background

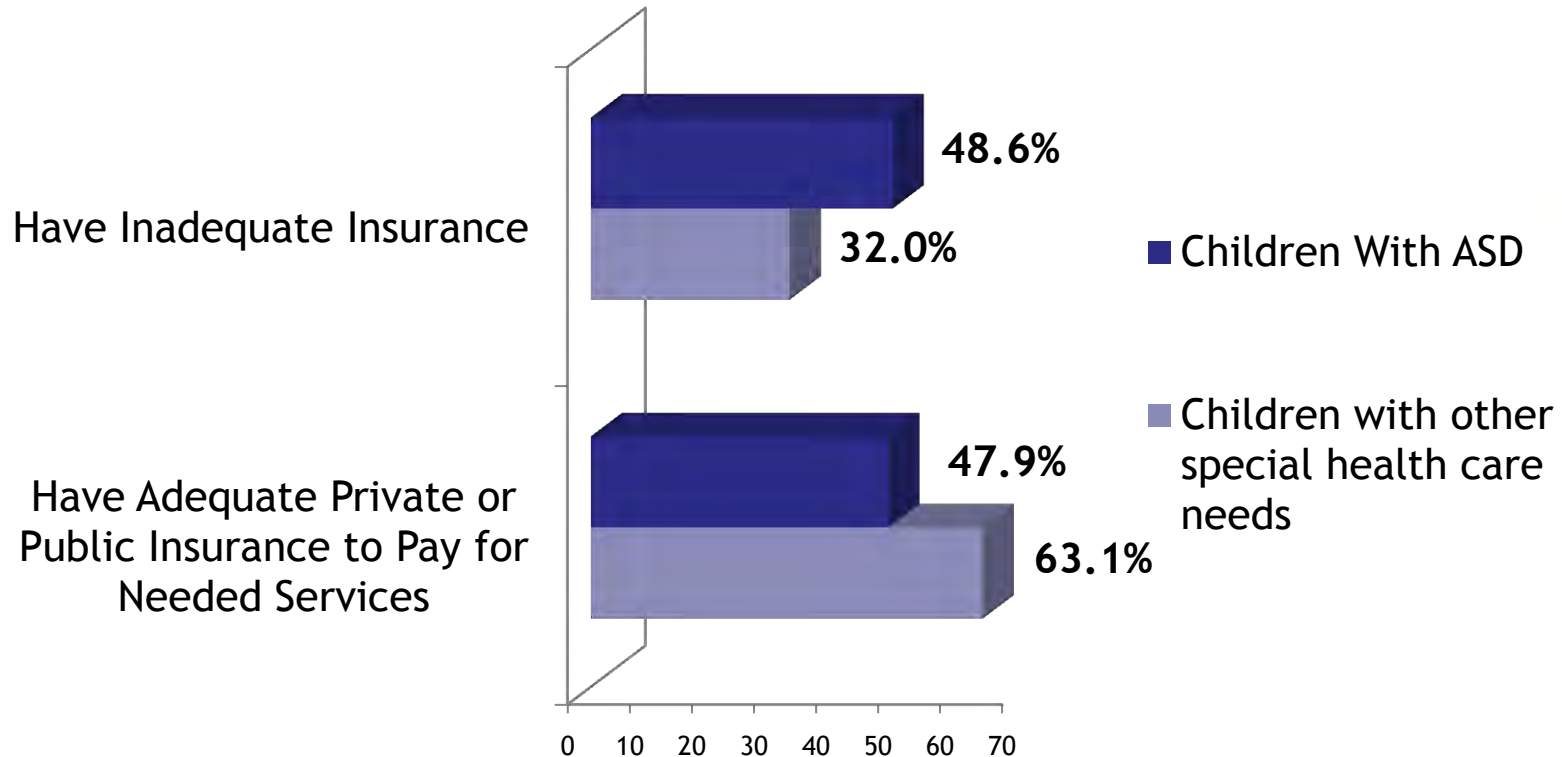
Individuals with Autism Spectrum Disorders (ASDs) have historically experienced difficulty with health insurance coverage.

- In a 2002 study of diagnostic exclusions in private behavioral health care plans, researchers who examined 46 employment-based behavioral health plans covering a total of 496,911 lives found that autism was a diagnostic exclusion in *all* of the plans.

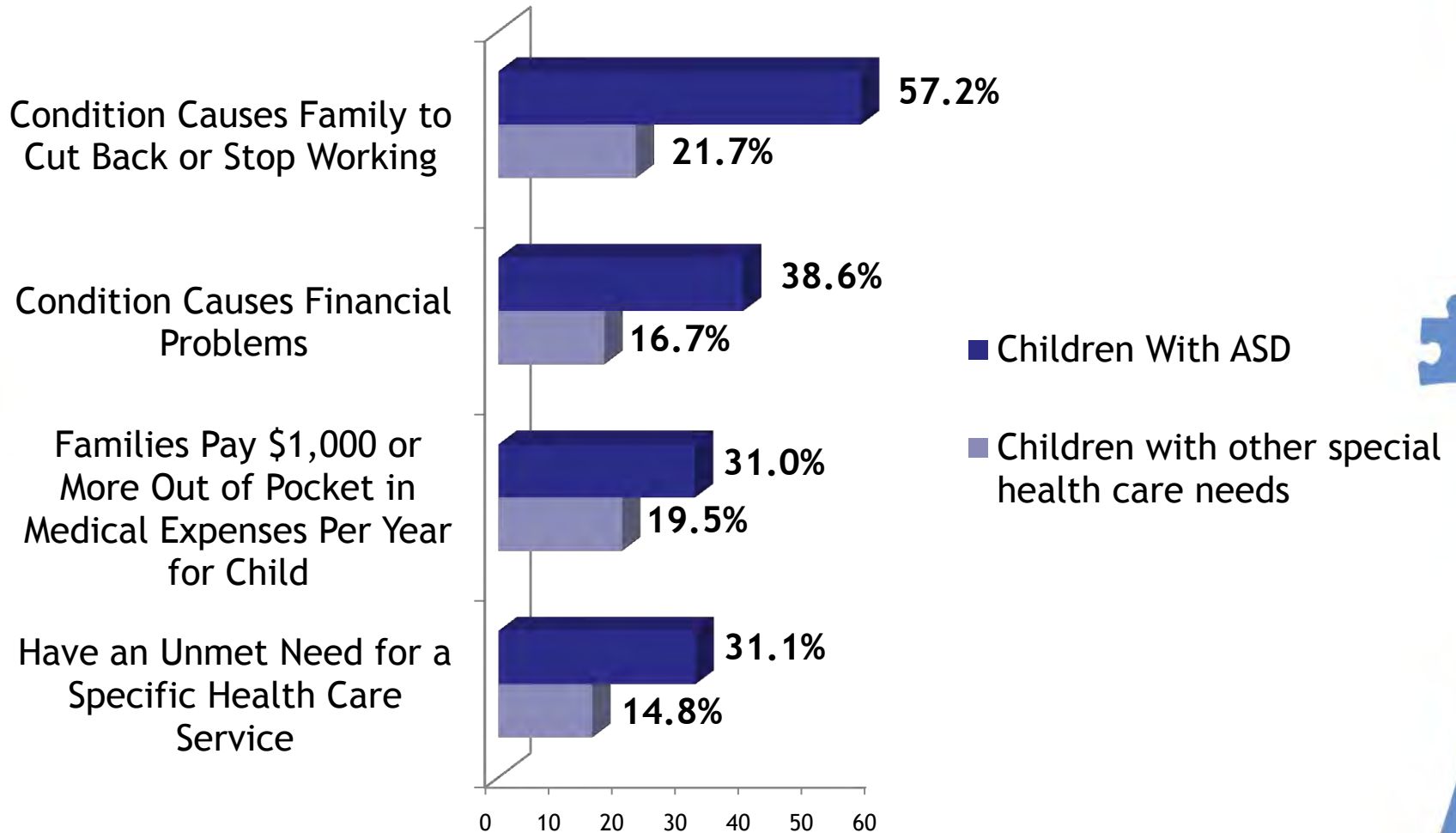


Background

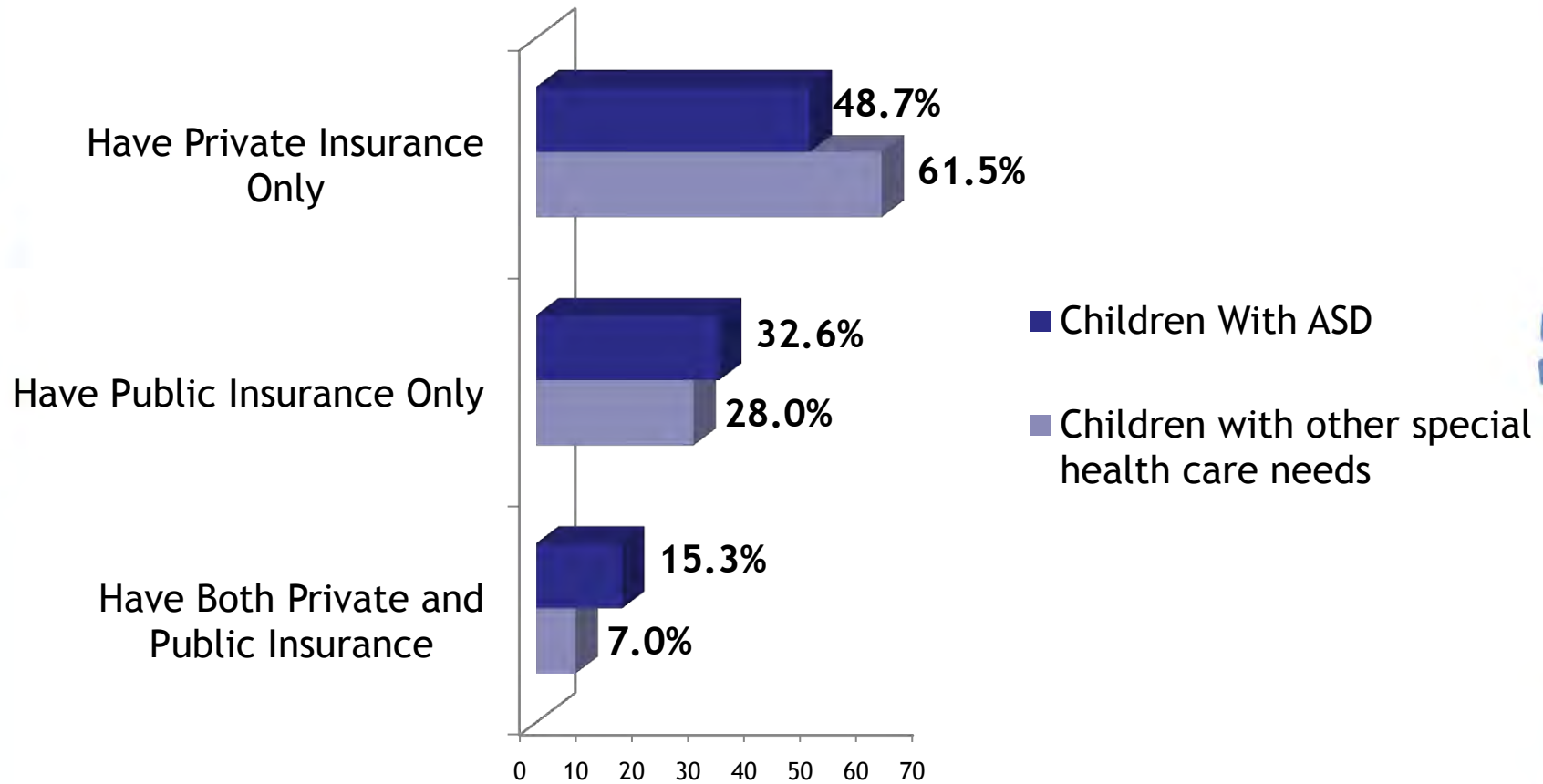
- According to the 2005/06 National Survey of Children with Special Health Care Needs,



Background



Background



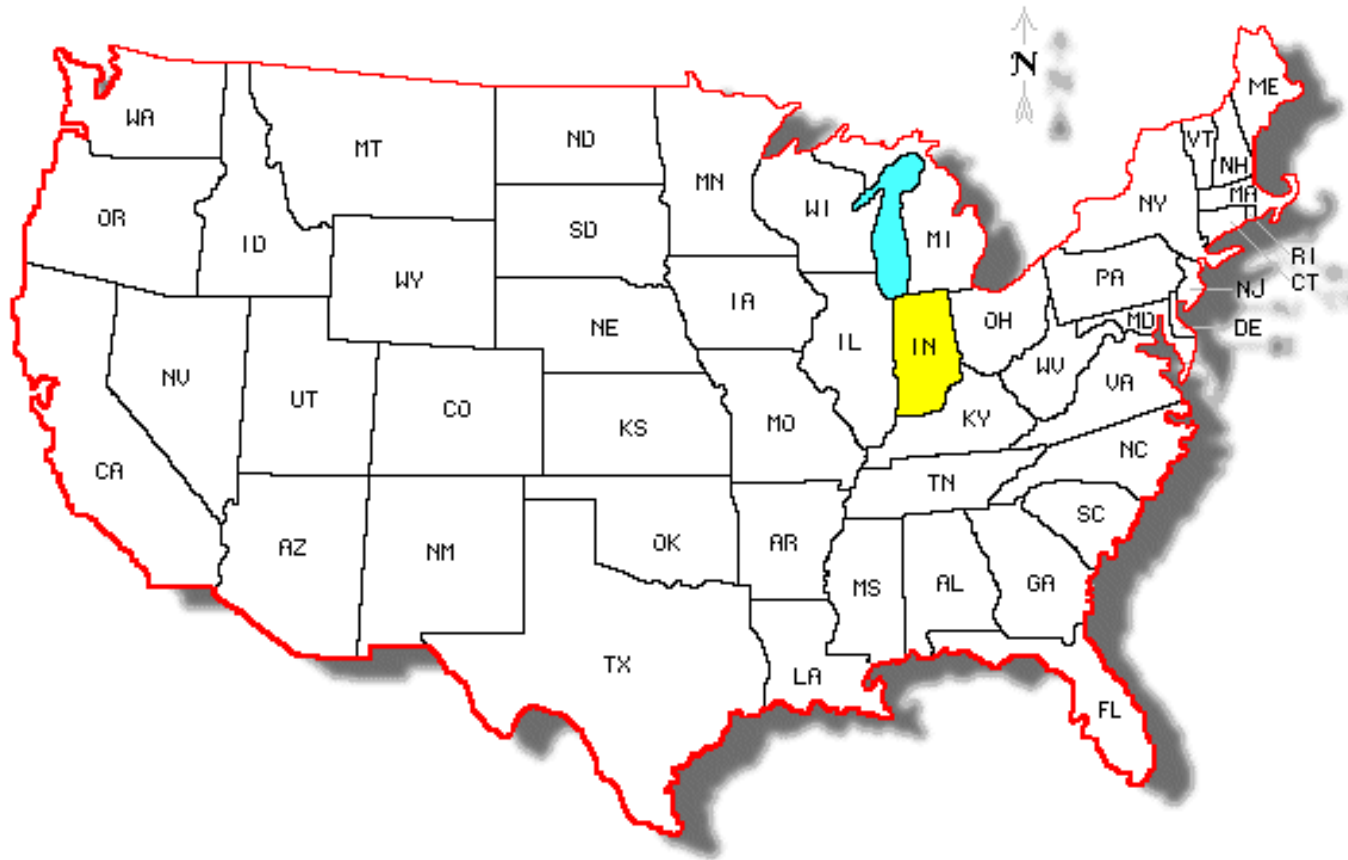
State Initiatives

Concern about the healthcare needs of individuals with autism has prompted enactment of state autism insurance laws.

- The first comprehensive statute dates back to 2001.



State Initiatives



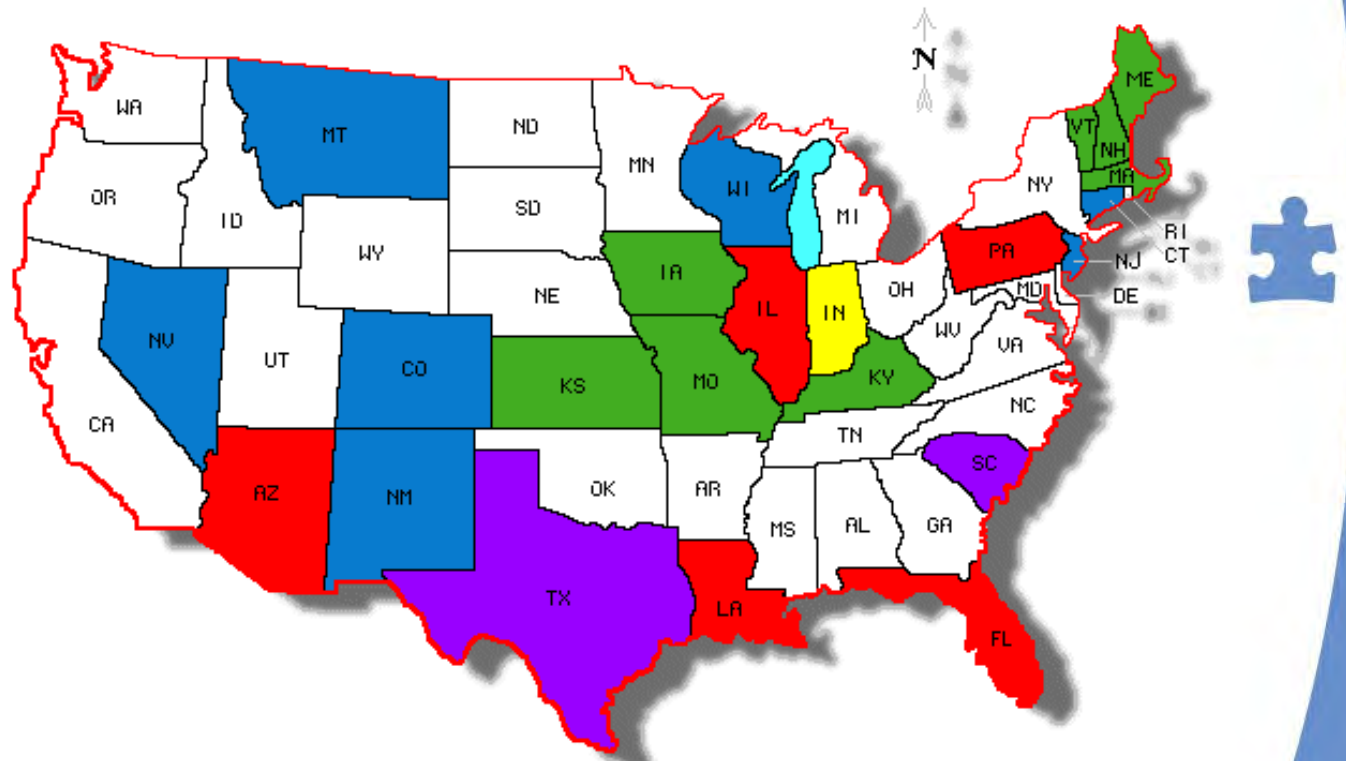
State Initiatives

- In 2007, Autism Speaks started a nationwide campaign to encourage enactment of comprehensive coverage laws for people with ASDs.
- There are now 23 states that have enacted strong benefit laws:



State Initiatives

- - Pre-2007
- - 2007
- - 2008
- - 2009
- - 2010



State Initiatives

- Each of the state laws differs, but most have these features:
 - coverage for diagnosis;
 - coverage for habilitative care, including speech therapy and occupational therapy;
 - coverage for applied behavior analysis;
 - protection for services rendered under the Individuals with Disabilities Education Act.
- Detailed information on each state law is available at www.autismvotes.org



State Initiatives

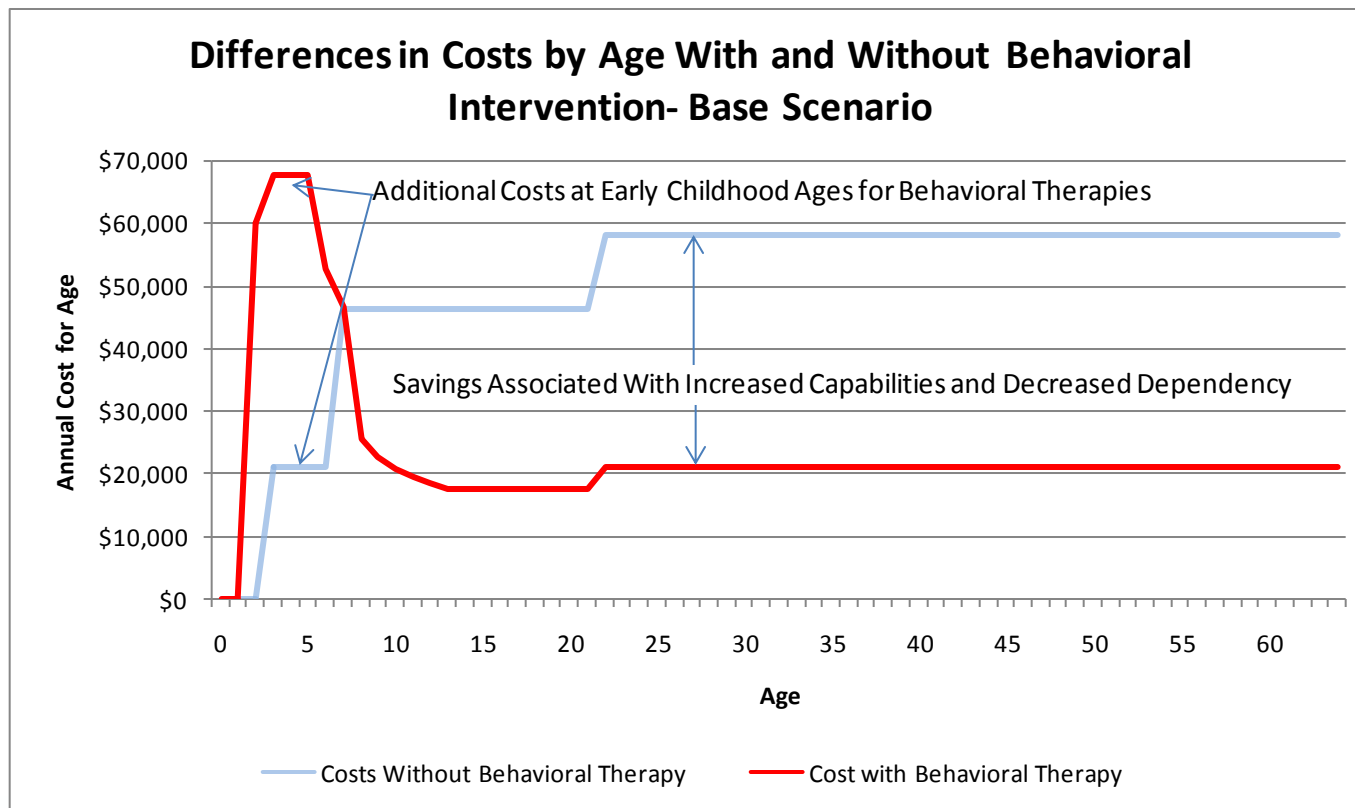
- The effect of these new laws on premiums is expected to be small. A national actuarial consulting firm estimates that state autism insurance laws may increase premiums by 0.3% to 0.6%:



Scenario	% Diagnosed Under Age 6 Starting ABA	Avg. Annual ABA Program Cost (Ages 2-7)	Avg. Annual non-ABA Cost	Annual Premium Increase per Person	Premium Increase (% of Premium)
Low	40.0%	\$35,000	\$2,050	\$11.20	0.28%
Middle	50.0%	\$42,500	\$3,075	\$16.90	0.42%
High	66.7%	\$49,496	\$4,100	\$25.60	0.64%

State Initiatives

It is expected that these cost increases will be offset by savings associated with decreased dependence.



State Initiatives

- Although millions of Americans have benefited from them, the reach of state insurance laws is limited:
 - 59% of covered workers are in a self-funded plan. The Employee Retirement Income Security Act of 1974 (ERISA) exempts self-funded plans from state insurance laws.
 - Medicaid, the Federal Employees Health Benefits program (FEHB), as well as other plans are not affected by state insurance laws.
 - About 1 in 6 Americans is uninsured.



Federal Initiatives - Autism Treatment Acceleration Act

The health care of people with autism is not solely a concern of state policymakers.

- In 2009 the Autism Treatment Acceleration Act (ATAA) was introduced in Congress. Sen. Richard Durbin (IL) sponsored the bill in the Senate and Rep. Mike Doyle (PA) sponsored a companion measure in the House.
- The bill reflected the commitment and interest of candidate and then President Obama in addressing ASD and its challenges:



Federal Initiatives - Autism Treatment Acceleration Act



OBAMA
BIDEN

WWW.BARACKOBAMA.COM



Federal Initiatives - Autism Treatment Acceleration Act

- “Barack Obama and Joe Biden will seek to increase federal ASD funding for research, treatment, screenings, public awareness, and support services to \$1 billion annually by the end of his first term in office. They will mandate insurance coverage of autism treatment and will also continue to work with parents, physicians, providers, researchers, and schools to create opportunities and effective solutions for people with ASD.”



Federal Initiatives - Autism Treatment Acceleration Act

- Both versions of the ATAA bill contained a comprehensive autism coverage provision, which defined ASD and required coverage for diagnosis and certain treatments, including the following:
 - Medications
 - Occupational therapy, physical therapy, and speech therapy
 - Services provided by a psychologist or psychiatrist
 - Applied behavior analysis
 - Augmentative communication devices.



Federal Initiatives - Autism Treatment Acceleration Act

- Both the House and Senate bills would have required coverage by self-funded and fully funded plans, as well as plans issued in the individual market.
- Notwithstanding the breadth of its congressional support - 21 cosponsors in the Senate and 86 in the House - ATAA was not enacted into law, as Congress' attention shifted to broad health care reform.



Federal Initiatives - the Patient Protection and Affordable Care Act

- Although the Patient Protection and Affordable Care Act (PPACA) does not specifically mention autism, it will have a profound effect on people with ASDs.
- Regulations under the act require group and individual coverage for certain preventive services, with no cost-sharing requirements. Covered services include the following:
 - Screening for developmental delays and disabilities during regular well-child doctor visits at 9 months, 18 months, 24 or 30 months, and additional necessary visits
 - Autism-specific screening during regular well-child doctor visits at 18 months, 24 months, and additional necessary visits



Federal Initiatives - the Patient Protection and Affordable Care Act

- Section 1302 of the PPACA describes 10 general categories of essential health benefits. One category is “Mental health and substance use disorder services, including behavioral health treatment.”
- This last phrase was introduced as an amendment in the House by Rep. Mike Doyle (PA), Congressional Autism Caucus co-chair, and Sen. Robert Menendez (NJ) in the Senate, where there was a lively debate.



Federal Initiatives - the Patient Protection and Affordable Care Act



Federal Initiatives - the Patient Protection and Affordable Care Act

- The Institute of Medicine (IOM) has been charged with making recommendations to the Secretary regarding the criteria and methods for determining the essential health benefits package.
- In separate letters to the President of the IOM, Senator Menendez, joined by Senators Durbin and Casey, and Representative Doyle confirmed that Congress intended to include applied behavior analysis in the essential health benefits.



Conclusion

- During the debate over the PPACA and beyond, Autism Speaks has vigorously argued for comprehensive health coverage for people with ASDs. We believe that the lives of people with ASDs can be significantly benefitted if this critical moment is seized and a decades-long pattern of discrimination in health care comes to an end.



Determination of Essential Health Benefits



AUTISM SOCIETY

Improving the Lives of All Affected by Autism

Jeff Sell, Esq.

VP, Public Policy & General Counsel

18 January 2011

ACA

- Section 1302(b)(1) lists ten general categories of essential health benefits, including “Mental health and substance use disorder services, including *“behavioral health treatment”* (section 1302(b)(1)(E)).
- The reference to behavioral health treatment was added by amendments in both the House and Senate.
- Must give effect to each provision of the Act, including section 1302(b)(1)

ACA

- The Congressional Budget Office (CBO) determined that Sen. Menendez's amendment did not require any cost offsets.
- The CBO concluded that the Menendez amendment clarified rather than expanded what the Senate Finance Committee Chairman's Mark required, namely, mental health and substance abuse services that at least met minimum standards set by federal and state laws.



Thank You

Jeff Sell, Esq.

***VP, Public Policy
& General Counsel***

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 **AUTISM SOCIETY**
Improving the Lives of All Affected by Autism

Lunch Break

Afternoon Agenda

1:30 Public Comments

1:45 Strategic Plan Update – Discussion and Votes
continued

2:45 Break

3:00 Update: IACC Subcommittee on Safety

Sharon Lewis, Lyn Redwood, R.N, M.S.N, and Alison Singer,
M.B.A.

3:45 OARC Update and IACC Planning Activities for 2011

Susan Daniels, Ph.D.

4:30 Public Comments Discussion Period

5:00 Adjournment

Meeting of the IACC

Open Session for Public Comment

Meeting of the IACC

Afternoon Agenda

1:30 Public Comments

1:45 Strategic Plan Update – Discussion and Votes
continued

2:45 Break

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3:45 OARC Update and IACC Planning Activities for 2011

Susan Daniels, Ph.D.

4:30 Public Comments Discussion Period

5:00 Adjournment

This meeting may end prior to or later than 5:30 PM ET, depending on the needs of the committee.

OARC Update and IACC Planning Activities for 2011

Susan Daniels, Ph.D.
Deputy Director, Office of Autism Research Coordination (OARC)
IACC Full Committee Meeting - January 18, 2011

OARC Staff Update

- Della Hann, Ph.D., Acting Director
- Susan Daniels, Ph.D., Deputy Director
- Elizabeth Baden, Ph.D., Policy Analyst
- Erin Bryant, M.J., Science Writer
- Sara Dodson, Ph.D., AAAS Science and Technology Policy Fellow
- Nicole Jones, Web Developer
- Lina Perez, Management Analyst

IACC Portfolio Analysis

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

2009 Portfolio Analysis Update

- ✓ Data call to collect information from funders
- ✓ Funders code projects according to Strategic Plan objectives
- ✓ Generate draft analysis
- Editing, coding verification, final analysis and opportunity to review
- Publish and distribute final report to IACC and the public – **Early 2011**

Proposal for 2010 Portfolio Analysis

OARC Data Request - Questions for funders:

- Number of research projects
- Total ASD Research Funding
- Project Titles, Principal Investigators/Institutions
- Project descriptions
- How Funded Projects Correspond to the IACC 2011 Strategic Plan (coding)

Possible new data to gather for the 2010 Portfolio Analysis:

- List of publications stemming from grants?

Participating ASD Research Funders from 2009 Portfolio Analysis

Federal Funders of ASD Research

- Centers for Disease Control and Prevention (CDC)
- Centers for Medicare and Medicaid Services (CMS)
- Department of Defense (DoD)
- Department of Education (Ed)
- Health Resource and Services Administration (HRSA)
- National Institutes of Health (NIH)

Private Funders of ASD Research

- Autism Research Institute (ARI)
- Autism Science Foundation (ASF)
- Autism Speaks (AS)
- Center for Autism and Related Disorders (CARD)
- Organization of Autism Research (OAR)
- The Simons Foundation (Simons)
- Southwest Autism Research and Resource Center (SARRC)

Proposed Timeline

- Data Call – Spring 2011
- Update IACC at April 11, 2011 Meeting
- Data analysis – Summer 2011
- Draft analysis to IACC – July 19, 2011 Meeting
- Completed analysis – September 2011

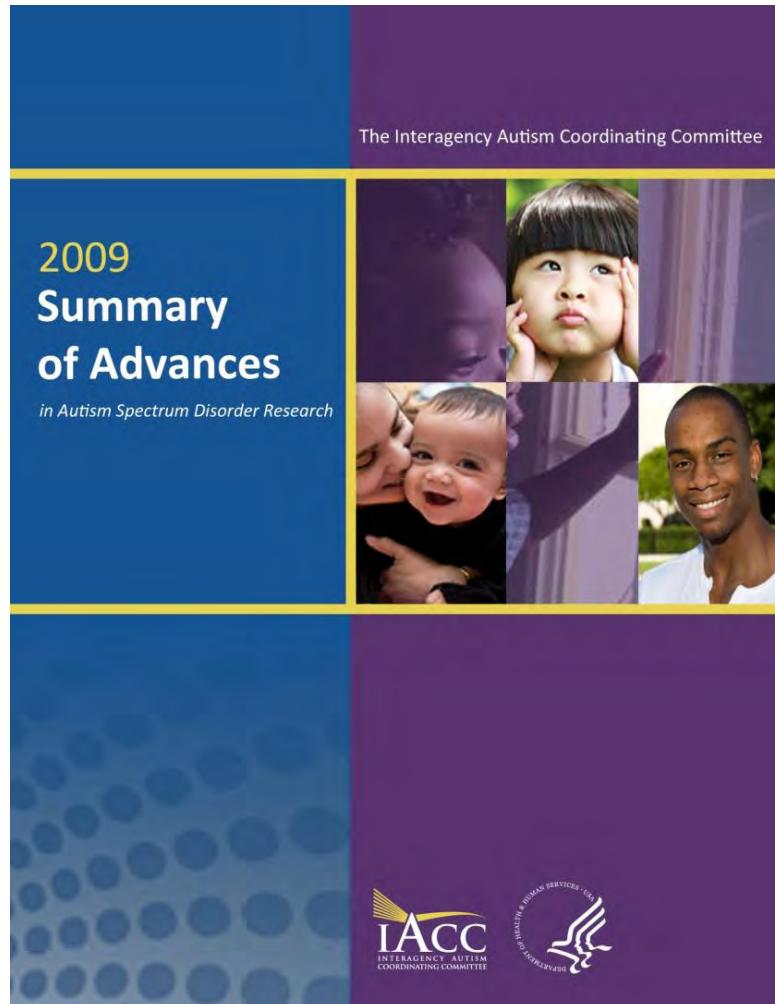
Summary of Advances

- Required by the Combating Autism Act of 2006

(Public Law 109-416 SEC. 399CC.(b)(1))

“Develop and annually update a summary of advances in autism spectrum disorder research related to causes, prevention, treatment, early screening, diagnosis or rule out, intervention, and access to services and supports for individuals with autism spectrum disorder...”

2009 Summary of Advances



- The IACC identified 20 peer-reviewed articles published in 2009 that they felt reflected the most significant advances in ASD biomedical and services research.
- These studies gave important new insight into the prevalence of autism spectrum disorder, the biology of the disorder, potential risk factors, and possible interventions.

2010 Summary of Advances

- The full document will include the 20 advances in the field of autism biomedical and services research deemed most significant by the IACC for calendar year 2010
- *Published research only – does not include advanced e-pubs*

2010 Summary of Advances: Part 1

- Mid-year Installment of 10 articles already completed:
 - Fall 2010 - IACC members nominated 3-5 articles each (34 total)
 - The IACC voted to select the first 10 articles to be included in the Summary

Mid-year Top 10

- **Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs: a consensus report.** (Buie et al., *Pediatrics*)
- **Randomized, controlled trial of an intervention for toddlers with autism: The Early Start Denver Model.** (Dawson et al., *Pediatrics*)
- **Functional impact of global rare copy number variation in autism spectrum disorders.** (Pinto et al., *Nature*)
- **Longitudinal magnetic resonance imaging study of cortical development through early childhood in autism.** (Schumann et al., *Journal of Neuroscience*)
- **Blood mercury concentrations in CHARGE Study children with and without autism.** (Hertz-Picciotto et al., *Environmental Health Perspectives*)

Mid-year Top 10 (continued)

- **Mutations in the SHANK2 synaptic scaffolding gene in autism spectrum disorder and mental retardation.** (Berkel et al., *Nature Genetics*)
- **A prospective study of the emergence of early behavioral signs of autism.** (Ozonoff et al., *Journal of the American Academy of Child and Adolescent Psychiatry*)
- **Changes in autism spectrum disorder prevalence in 4 areas of the United States.** (Rice et al., *Disability and Health Journal*)
- **Consensus statement: Chromosomal microarray is a first-tier clinical diagnostic test for individuals with developmental disabilities or congenital anomalies.** (Miller et al., *American Journal of Human Genetics*)
- **Implementing developmental screening and referrals: lessons learned from a national project.** (King et al., *Pediatrics*)

2010 Summary of Advances: Part 2

- Final Installment to be completed:
 - Ten additional 2010 articles to be identified
 - IACC members will nominate 3-5 articles each:
 - OARC will redistribute articles listed in the Mid-year ballot
 - IACC members may nominate additional articles published anytime in 2010
 - OARC will compile 2nd Installment ballot and distribute to IACC members
 - IACC will vote to select the final 10 articles to complete the 2010 Summary

2010 Summary of Advances

- Final Product to be produced by OARC:
 - Collection of independent short summaries of the top 20 ASD research papers, organized according to topics covered in the Strategic Plan
- Timeline:
 - Winter/Spring 2011 – Selection of 2nd Installment
 - Draft document with all 20 articles to be presented to IACC in April 2011 for approval
 - Final 2010 IACC Summary of Advances to be released in April 2011

Future IACC Activities

- Gathering input from the research community and the public:
 - Workshop or Town Hall Meeting?
 - RFI?

Meeting of the IACC

Public Comments: Discussion Period

Upcoming IACC Meetings

Full IACC Meetings

- April 11, 2011
- July 19, 2011

Meeting of the IACC

Adjournment