

# Meeting of the Interagency Autism Coordinating Committee

April 8, 2014

National Institutes of Health  
31 Center Drive, Building 31  
C Wing, 6<sup>th</sup> Floor, Room 10  
Bethesda, MD 20892

**Conference Call Access:**

Phone: (888) 950-8042

Access Code: 8689681

# Meeting of the IACC

---

## Morning Agenda

**9:00 AM      Welcome and Introductions**

**Thomas Insel, M.D.**

Director, NIMH and Chair, IACC

**Susan Daniels, Ph.D.**

Director, OARC, NIMH and Executive  
Secretary, IACC

**9:15            Science Update**

**Thomas Insel, M.D.**

Director, NIMH and Chair, IACC

# Meeting of the IACC

---

## Science Update

**Thomas R. Insel, M.D.**

Director, National Institute of Mental Health and Chair, IACC  
IACC Full Committee Meeting – April 8, 2014

# Q1. When should I be concerned?

---



February 19, 2014

## **Longitudinal patterns of repetitive behavior in toddlers with autism**

Wolff JJ, Botteron KN, Dager SR, Elison JT, Estes AM, Gu H, Hazlett HC, Pandey J, Paterson SJ, Schultz RT, Zwaigenbaum L, Piven J.



March 13, 2014

## **Genetically meaningful phenotypic subgroups in autism spectrum disorders**

Veatch OJ, Veenstra-Vanderweele J, Potter M, Pericak-Vance MA, Haines JL.

## **The broader autism phenotype in infancy: when does it emerge?**

Ozonoff S, Young GS, Belding A, Hill M, Hill A, Hutman T, Johnson S, Miller M, Rogers SJ, Schwichtenberg AJ, Steinfeld M, Iosif AM.

### **Longitudinal study - 294 high risk and 116 low risk: 6, 12, 18, 24, 36 mos.**

- Close to 50% of younger siblings of children with ASD develop in an atypical fashion. In the current study, 17% developed ASD, and another 28% showed delays or deficits in other areas of development or behavior.
- Differences in development are detectable using standardized assessment instruments by **12 months of age** in many children.
- The most common development differences seen in younger siblings of children with ASD are delays in social-communication development (including reduced eye contact, extreme shyness with unfamiliar persons, and delayed onset of gestures and speech). Some younger siblings also show delays in cognitive and motor abilities, as well as attentional and behavioral problems.

# Q2. How can I understand what is happening?

---



January 16, 2014

## **CNVs conferring risk of autism or schizophrenia affect cognition in controls**

Stefansson H, Meyer-Lindenberg A, Steinberg S, Magnusdottir B, Morgen K, Arnarsdottir S, Bjornsdottir G, Walters GB, Jonsdottir GA, Doyle OM, Tost H, Grimm O, et. al.



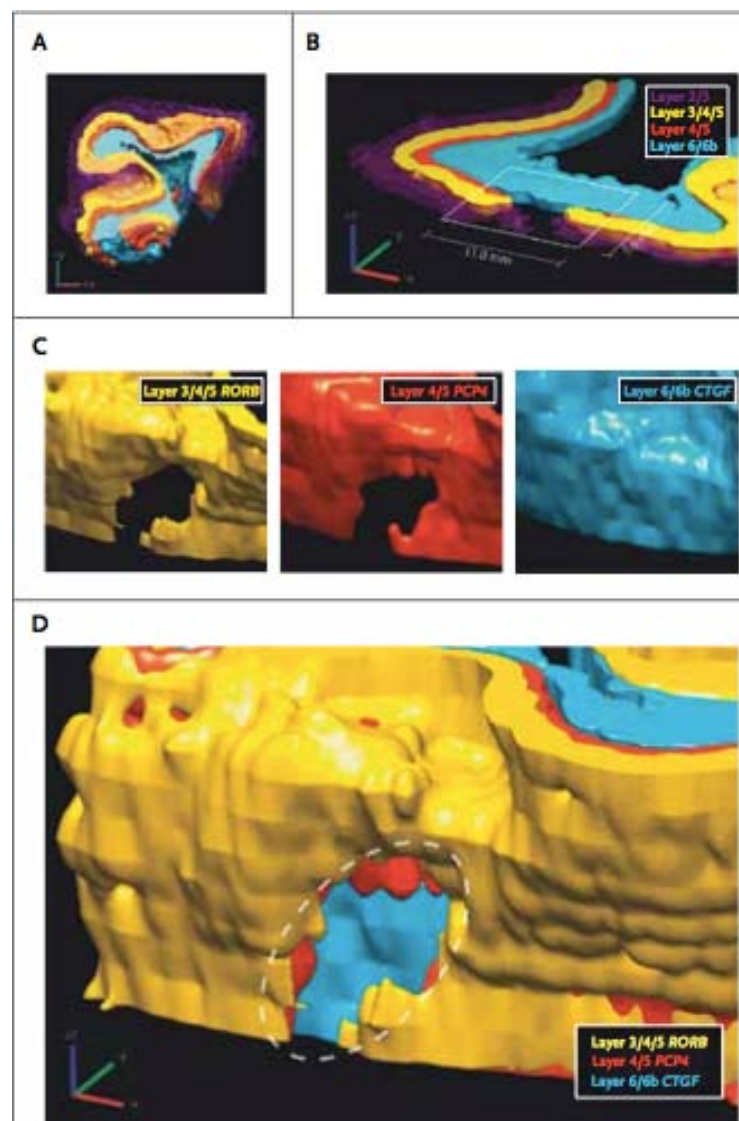
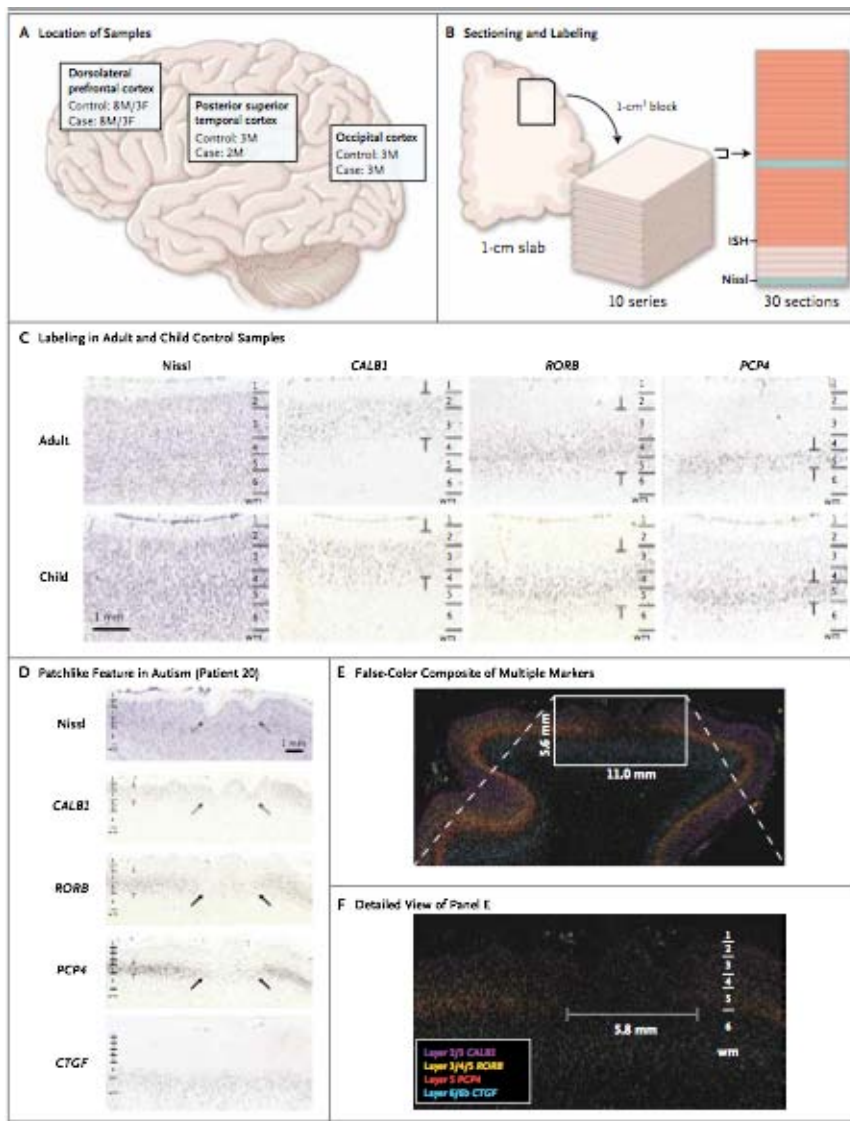
February 4, 2014

## **Differences in the right inferior longitudinal fasciculus but no general disruption of white matter tracts in children with autism spectrum disorder**

Koldewyn K, Yendiki A, Weigelt S, Gweon H, Julian J, Richardson H, Malloy C, Saxe R, Fischl B, Kanwisher N.

# Patches of disorganization in the neocortex of children with autism

Stoner R, Chow ML, Boyle MP, Sunkin SM, Mouton PR, Roy S, Wynshaw-Boris A, Colamarino SA, Lein ES, Courchesne E.





# Q3. What caused this to happen and can it be prevented?

---

The JOURNAL  
of PEDIATRICS

January 2014

## **Prevalence and neonatal factors associated with autism spectrum disorders in preterm infants**

Kuzniewicz MW, Wi S, Qian Y, Walsh EM, Armstrong MA, Croen LA.

nature  
genetics

April 2014

## **A SWI/SNF- related autism syndrome caused by de novo mutations in ADNP**

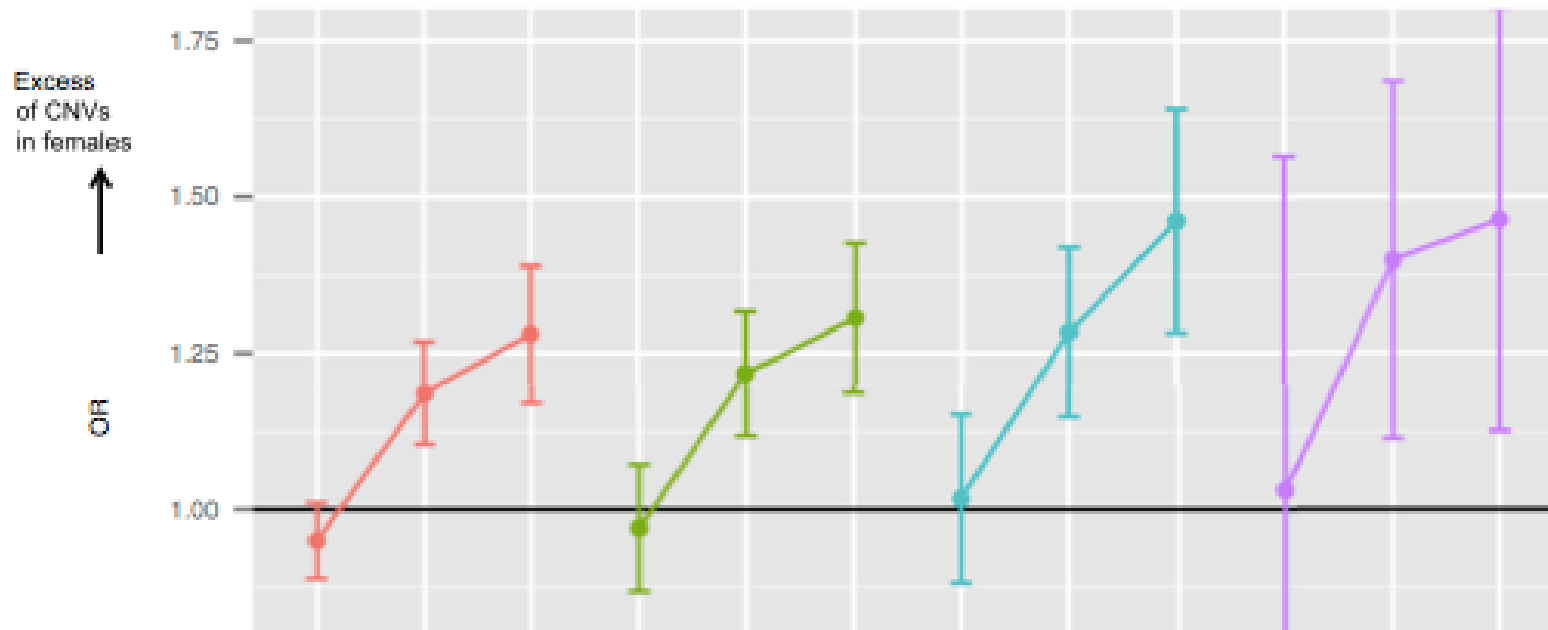
Helsmoortel C, Vulto-van Silfhout AT, Coe BP, Vandeweyer G, Rooms L, van den Ende J, Schuurs-Hoeijmakers JH, Marcelis CL, Willemsen MH, Vissers LE, Yntema HG, Bakshi M, Wilson M, et. al.



# A higher mutational burden in females supports a "female protective model" in neurodevelopmental disorders

Jacquemont S, Coe BP, Hersch M, Duyzend MH, Krumm N, Bergmann S, Beckmann JS, Rosenfeld

	<1%			<1% and "ND list"			<0.1% and "ND list"			de novo CNVs		
Size	400 kb	1 Mb	>	400 kb	1 Mb	>	400 kb	1 Mb	>	400 kb	1 Mb	>
CNVs in 9,206 Males	5,023	2,764	1,425	995	1,610	1,183	581	857	576	42	206	159
CNVs in 6,379 Females	3,399	2,152	1,212	671	1,309	1,031	409	743	567	30	198	158
OR	-	1.18	1.28	-	1.21	1.30	-	1.28	1.46	-	1.39	1.46
p value	ns	$1 \times 10^{-6}$	$9 \times 10^{-9}$	ns	$2 \times 10^{-6}$	$7 \times 10^{-9}$	ns	$3 \times 10^{-6}$	$8 \times 10^{-10}$	ns	$1 \times 10^{-3}$	$8 \times 10^{-4}$



# Q4. Which treatments and interventions will help?

---

*Journal of the American Academy of*  
**CHILD & ADOLESCENT  
PSYCHIATRY**

February 2014

## **Preschool-based social communication treatment for children with autism: 12-month follow-up of a randomized trial**

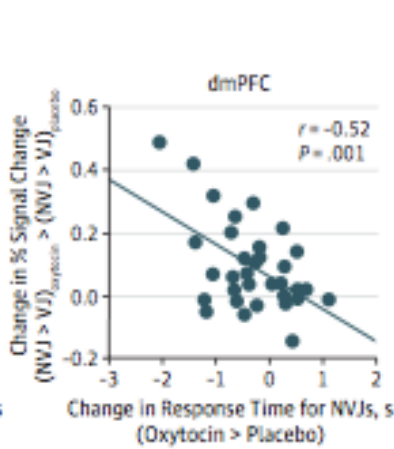
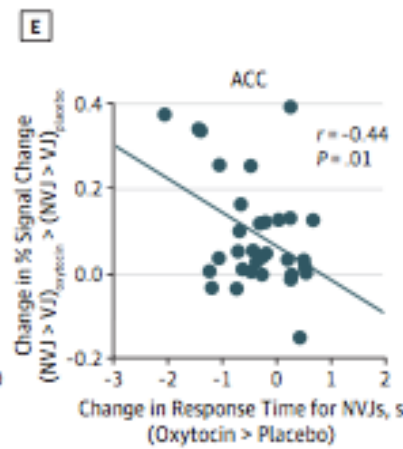
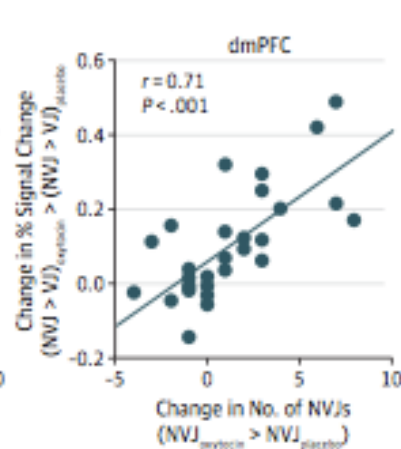
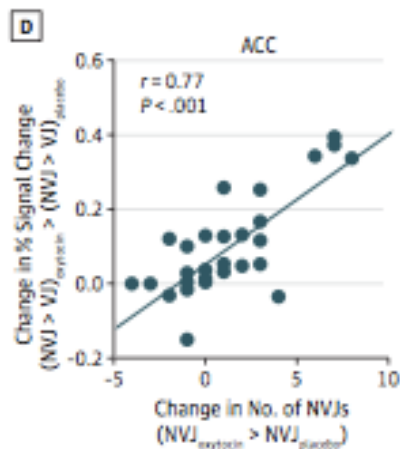
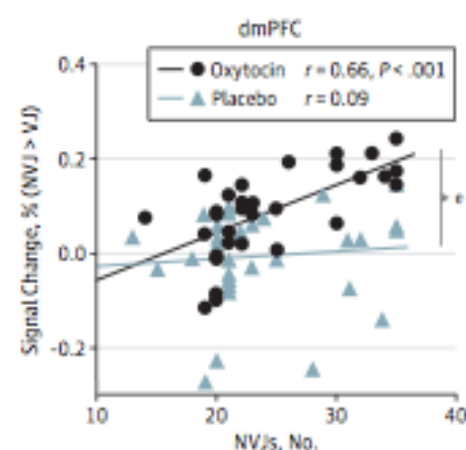
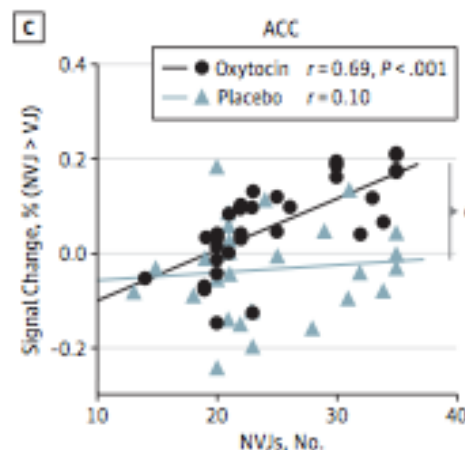
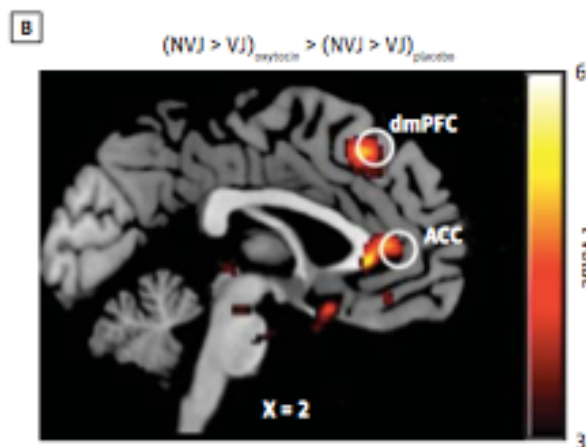
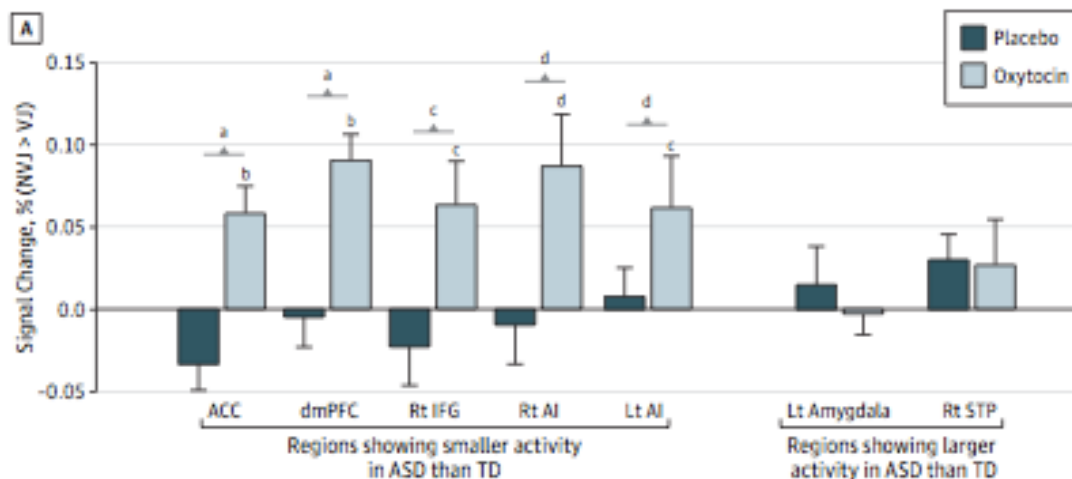
Kaale A, Fagerland MW, Martinsen EW, Smith L.

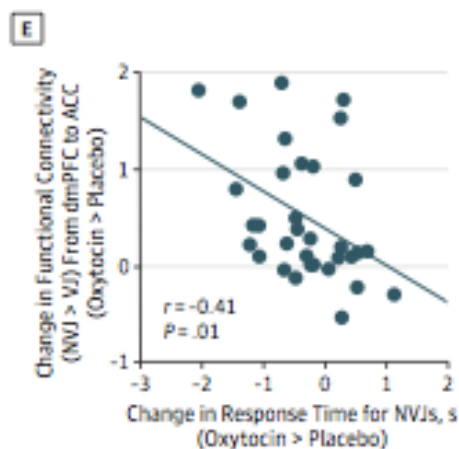
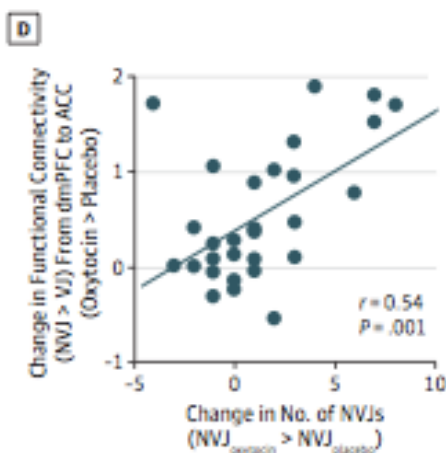
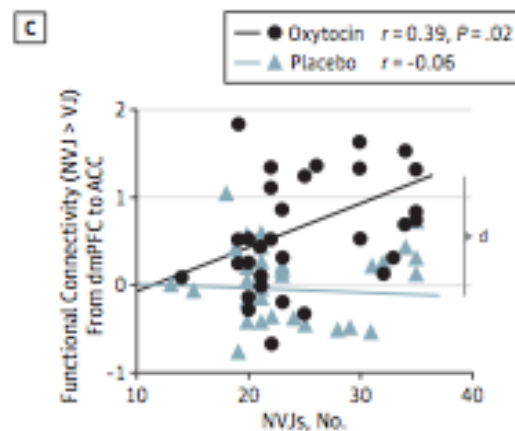
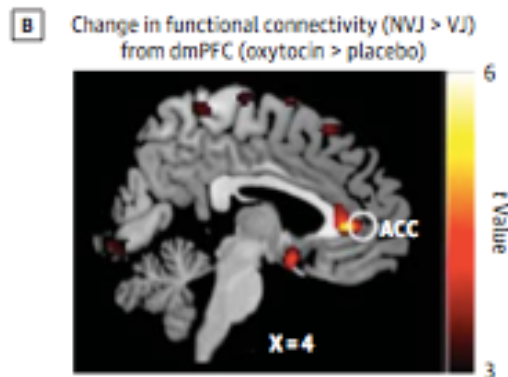
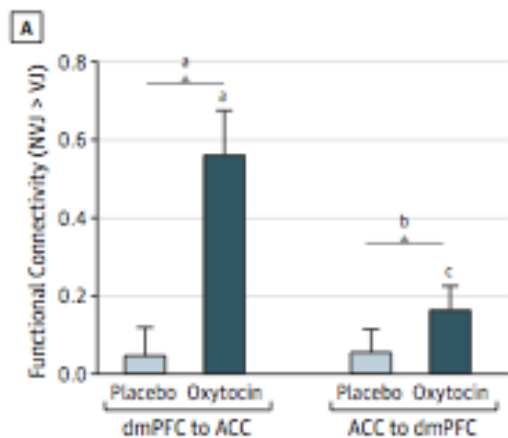


August 30, 2013

## **Two to Ten Years: Developmental Trajectories of Joint Attention in Children With ASD Who Received Targeted Social Communication Interventions**

Gulsrud AC, Helleman GS, Freeman SF, Kasari C.





# Q5. Where can I turn for services?

## PSYCHIATRIC SERVICES

A Journal of the  
American Psychiatric  
Association

March 1, 2014

### Health care experiences and perceived financial impact among families of children with an autism spectrum disorder

Zablotsky B, Kalb LG, Freedman B, Vasa R, Stuart EA.

## PEDIATRICS®

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

March 2014

### Economic burden of childhood autism spectrum disorders

Lavelle TA, Weinstein MC, Newhouse JP, Munir K, Kuhlthau KA, Prosser LA.

**TABLE 4** Summary of the Regression-Adjusted Difference in Costs for Children With ASD Compared With Children Without ASD

Category	Total costs, <sup>a</sup> \$	95% CI	Out of pocket costs <sup>a</sup> , \$	95% CI
Health care	3020	1017 to 4259	182	−6 to 299
Total aggregate non-health care	14 061	4390 to 24 302	−112	−715 to 749
School	8610	6595 to 10 421	−462	−3496 to 189
ASD-related therapy and other family-coordinated services	350	−76 to 972	81	−318 to 523
Time	5089	−1672 to 11 936	—	—

<sup>a</sup> Adjusted for child gender, age, race/ethnicity, insurance status, household income, geographic region, urban/rural classification, and the presence of a comorbidity not related to ASD.

# Q6. What does the future hold, particularly for adults?



January 2014

## **Cognitive and language skills in adults with autism: a 40-year follow-up**

Hendrie D, Gadow K, Masi D, Tannock A, Butler M



January 2014

## **Employment outcomes of transition-aged adults with autism spectrum disorders: a state of the States report**

Burgess S, Cimera RE.

The International Journal of Research and Practice • Volume 18 Number 1 January 2014



January 17, 2014

## **Quality of life in autism across the lifespan: A meta-analysis.**

van Heijst BF, Geurts HM.

# Q7. What other infrastructure and surveillance needs must be met?

---

## **JAMA Psychiatry**

*Formerly Archives of General Psychiatry*

March 1, 2014

### **Potential Impact of DSM-5 Criteria on Autism Spectrum Disorder Prevalence Estimates.**

Maenner MJ, Rice CE, Arneson CL, Cunniff C, Schieve LA, Carpenter LA, Van Naarden Braun K, Kirby RS, Bakian AV, Durkin MS.



March 28, 2014

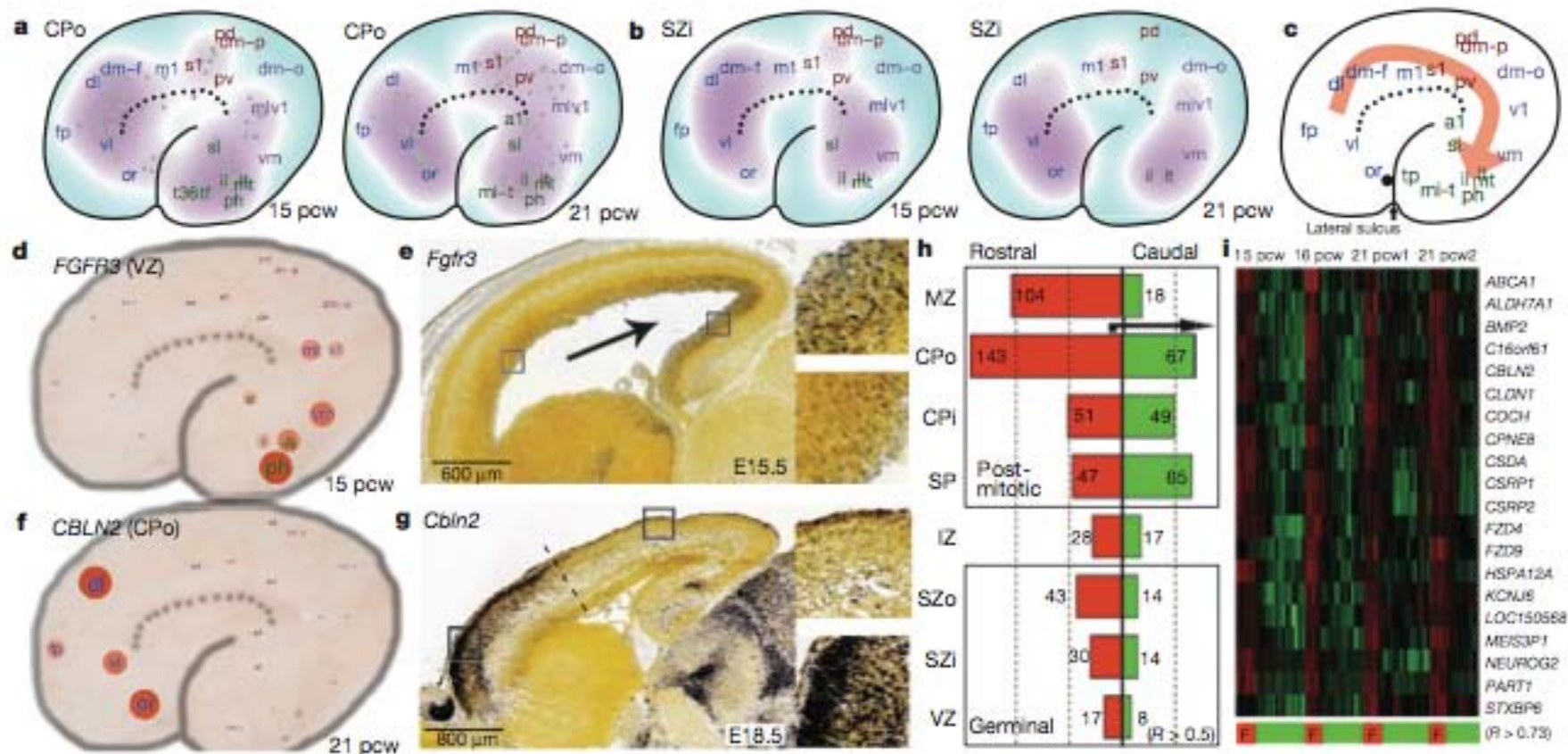
### **Prevalence of autism spectrum disorder among children aged 8 years - autism and developmental disabilities monitoring network, 11 sites, United States, 2010.**

Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators.



# Transcriptional landscape of the prenatal human brain.

Miller JA, Ding SL, Sunkin SM, Smith KA, Ng L, Szafer A, Ebbert A, Riley ZL<sup>2</sup> Royall JJ, Aiona K, Arnold JM, Bennet C, Bertagnolli D, Brouner K, Butler S, Caldejon S, Carey A, Cuhacian C, Dalley RA, et al.



# Meeting of the IACC

---

## Morning Agenda - continued

**9:30 AM      CDC Prevalence**

**Jon Baio, Ed.S.**

Epidemiologist,

US Centers for Disease Control (CDC)

**10:00              Birth to 5: Watch Me Thrive!**

**Linda Smith**

Deputy Assistant Secretary

Administration for Children and Families  
(ACF)

# Meeting of the IACC

---

## Centers for Disease Control Prevalence

**Jon Baio, Ed.S.**  
Epidemiologist  
U.S. Centers for Disease Control (CDC)

# **CDC Informational Briefing on Autism: Findings from the Latest Prevalence Report**

**Autism and Developmental Disabilities Monitoring (ADDM) Network  
11 Sites, United States, 2010**

Presented for the ADDM Network by Jon Baio, Ed.S., Epidemiologist  
National Center on Birth Defects and Developmental Disabilities  
Centers for Disease Control and Prevention

**Meeting of the Interagency Autism Coordinating Committee  
National Institutes of Health  
Bethesda, Maryland  
April 8, 2014**



# How common is Autism Spectrum Disorder?

Estimates of population prevalence vary widely across time and space

- **Different case ascertainment methods**
  - National or community surveys
  - Clinical samples or registries
  - Record-review methodology
- **Different case definitions**
  - Parent report of historical diagnosis
  - Diagnostic criteria (DSM-III, III-R, IV, IV-TR, 5)
  - Diagnostic instruments (screening checklists, observational tools)
- **Challenges in tracking autism prevalence**
  - Complex nature of the disorders
  - Lack of biologic markers for diagnosis

# Expansion of CDC's Developmental Disabilities Surveillance Programs

[Congress](#) > [Legislation](#)

## H.R. 4365: Children's Health Act of 2000

106<sup>th</sup> Congress ⓘ  
1999-2000

To amend the Public Health Service Act with respect to children's health.

**SEC. 102.** Developmental disabilities surveillance and research programs.

**(a)** National Autism and Pervasive Developmental Disabilities Surveillance Program.

**(1)** In general. The Secretary of Health and Human Services... acting through the Director of the Centers for Disease Control and Prevention, may make awards of grants and cooperative agreements for the collection, analysis, and reporting of data on autism and pervasive developmental disabilities...

**(2)** Eligibility. To be eligible to receive an award under paragraph (1) an entity shall be a public or nonprofit private entity (including health departments of States and political subdivisions of States, and including universities and other educational entities).

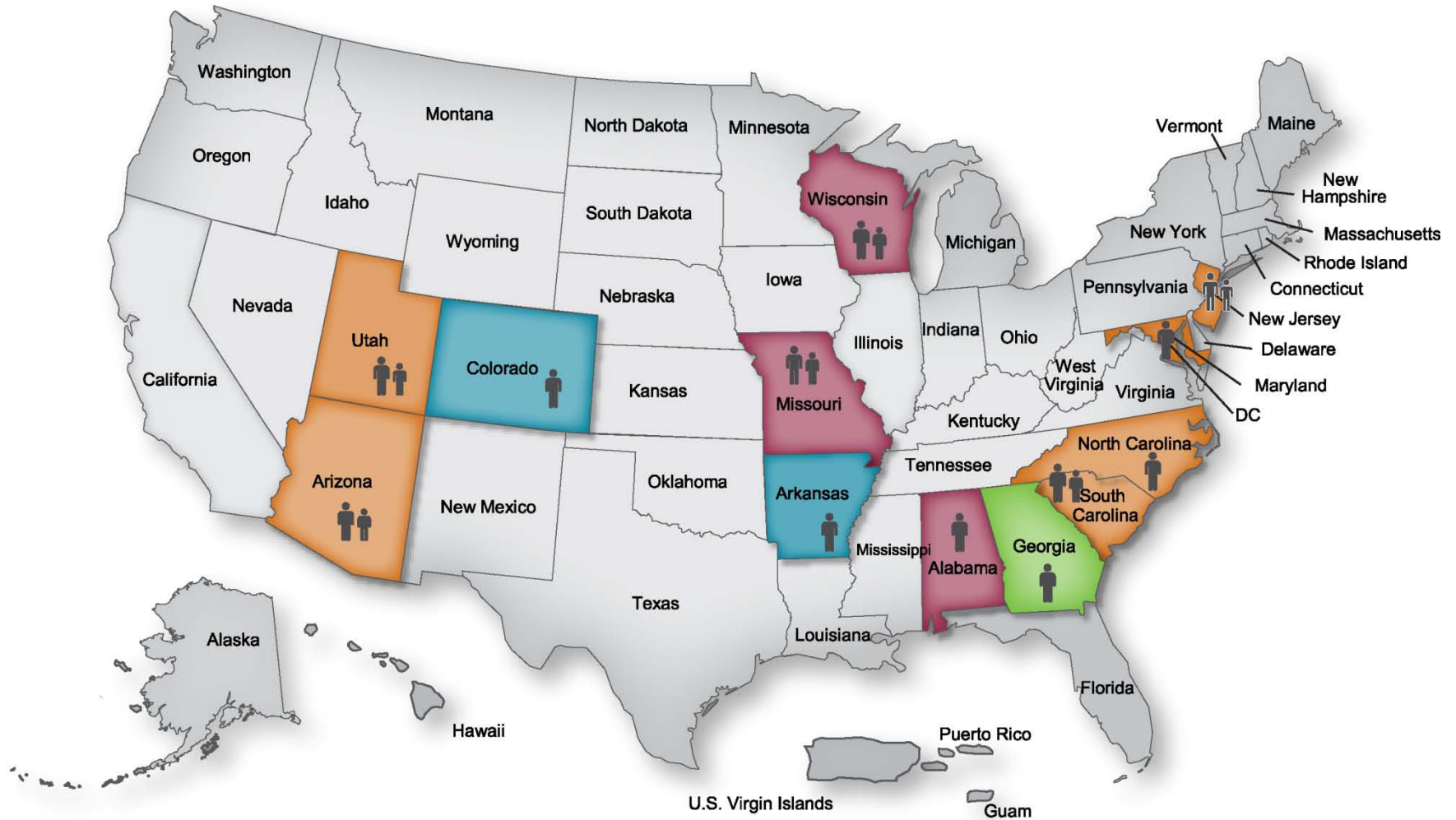




**Working together to understand the magnitude and characteristics of the population of children with autism and related developmental disabilities to inform science and policy**





- **Currently there are 11 funded ADDMM sites, plus CDC/MADDSP**
- **Autism prevalence among 8 year olds is monitored in all sites**
- **Piloting autism surveillance among 4 year olds in six sites**
- **Some sites also track Cerebral Palsy (4) and/or Intellectual Disability (7)**



# Current ADDM Network Sites, Surveillance Years 2010 and 2012



 Monitoring 8 year olds  
 Monitoring 4 and 8 year olds

 Autism  
 Autism, Cerebral Palsy  
 Autism, Intellectual Disability  
 Autism, Cerebral Palsy, Intellectual Disability, Vision Impairment, and Hearing Loss

## ADDM Network Methods

- Multisite, multisource (educational and healthcare settings), records-based surveillance methodology

Screening and abstraction  
of records at multiple data  
sources in community

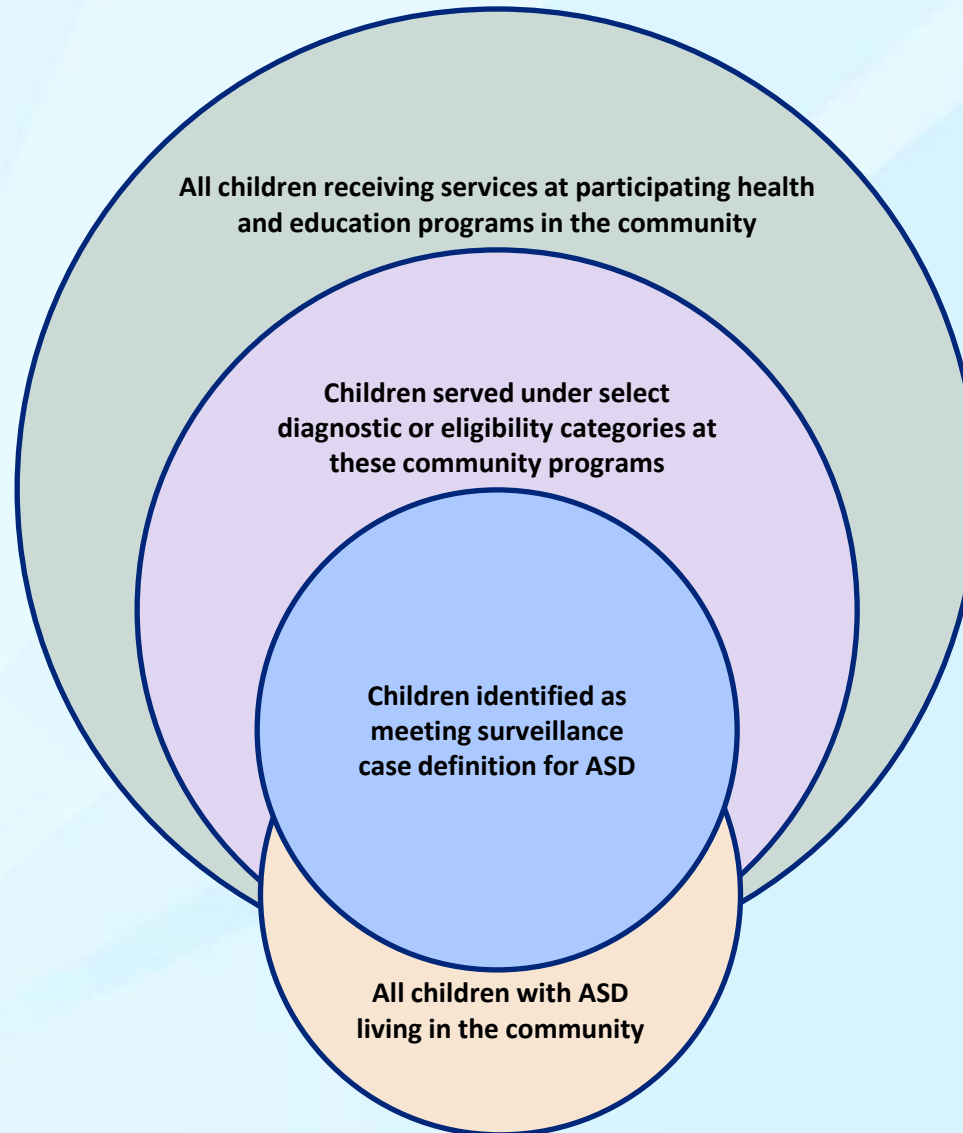


All abstracted evaluations  
reviewed by trained  
clinicians to determine  
ASD case status

# Evaluating Data Quality and Completeness

- Abstraction Quality Control
  - 10% sample of all “abstracted” records checked for accuracy of content
  - 10% sample of all “reviewed not abstracted” records checked for triggers
- Clinician Review Interrater Agreement
  - 10% sample of all records double-blind reviewed by 2 clinicians to check IRR
  - Target interrater agreement: 90% for final case status, 85% for eval diagnosis, 80% for all other coded items
  - All “low certainty” cases reviewed by 2 clinicians to reach consensus on final case status based on clinical judgment
- Validation study completed in Fulton County, Georgia
  - High positive predictive value (79%); higher when factoring in clinical judgment
  - Low sensitivity (60%); offset somewhat by “file not found” sensitivity analysis

# ADDM Casefinding Net



# MADDSP/ADDM Methodology

- Strengths

- Large, population-based study of autism (vs. studies done on small samples)
- Record review methodology maximizes population coverage (vs. direct screening, which is more costly, time-consuming, voluntary, restricted)
- Multiple-source case ascertainment, including both health and special education records in most sites
- Coding scheme and systematic review of behavioral descriptions to determine case status (based on DSM-IV-TR diagnostic criteria)
- Information on presence of other developmental disabilities

- Limitations

- Underascertainment of children with undocumented symptoms, children not being served in abstraction facilities / public special education programs
- Imprecision of population counts, especially in latter part of each decade when postcensal projections may become less accurate

# ADDM Network Autism Prevalence Reports



- **2007:** First report in MMWR SS - 2000 & 2002 surveillance years
  - **1 in 150** 8-year-old children in these communities were identified with ASD
- **2009:** Second report in MMWR SS - 2004 & 2006 surveillance years
  - **1 in 110** 8-year-old children in these communities were identified with ASD
  - Autism prevalence **increased 57%** between 2002 and 2006
- **2012:** Third report in MMWR SS - 2008 surveillance year
  - **1 in 88** 8-year-old children in these communities were identified with ASD
  - Detailed comparisons to earlier ADDM surveillance years (2002 & 2006)
    - Autism prevalence increased 78% between 2002 and 2008
    - Autism prevalence increased 23% between 2006 and 2008

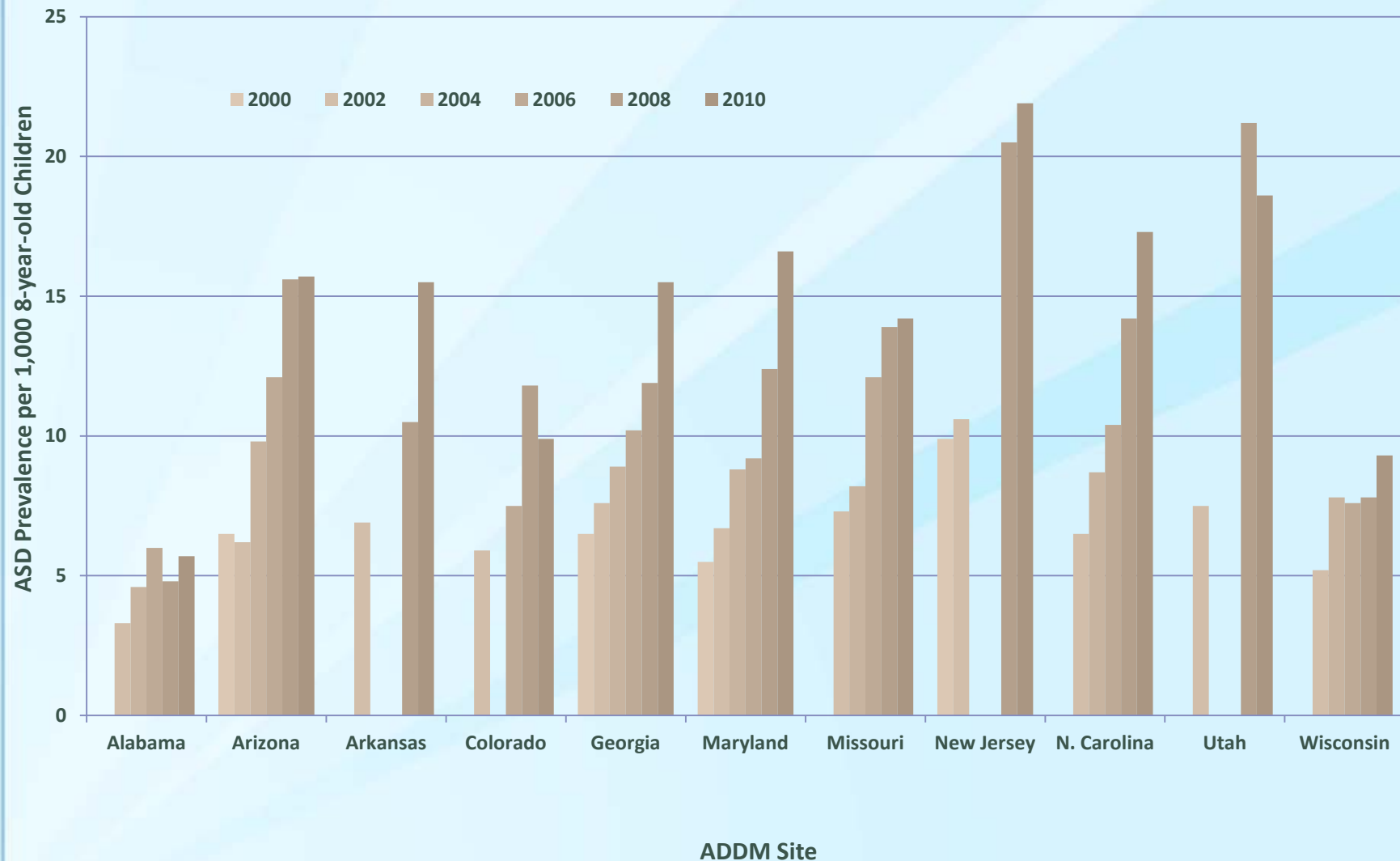
# ADDM Network ASD Prevalence Results

Combining Data from All Sites

Surveillance Year	Birth Year	Number of ADDM Sites Reporting	8-year-old Population	Number of children with ASD	Prevalence per 1,000 Children (Range among Sites)
2000	1992	6	187,761	1,252	6.7 (4.5-9.9)
2002	1994	14	407,578	2,685	6.6 (3.3-10.6)
2004	1996	8	172,335	1,376	8.0 (4.6-9.8)
2006	1998	11	308,038	2,757	9.0 (4.2-12.1)
2008	2000	14	337,093	3,820	11.3 (4.8-21.2)
2010	2002	11	363,749	5,338	14.7 (5.7-21.9)



# Change in ASD Prevalence Among ADDM Sites



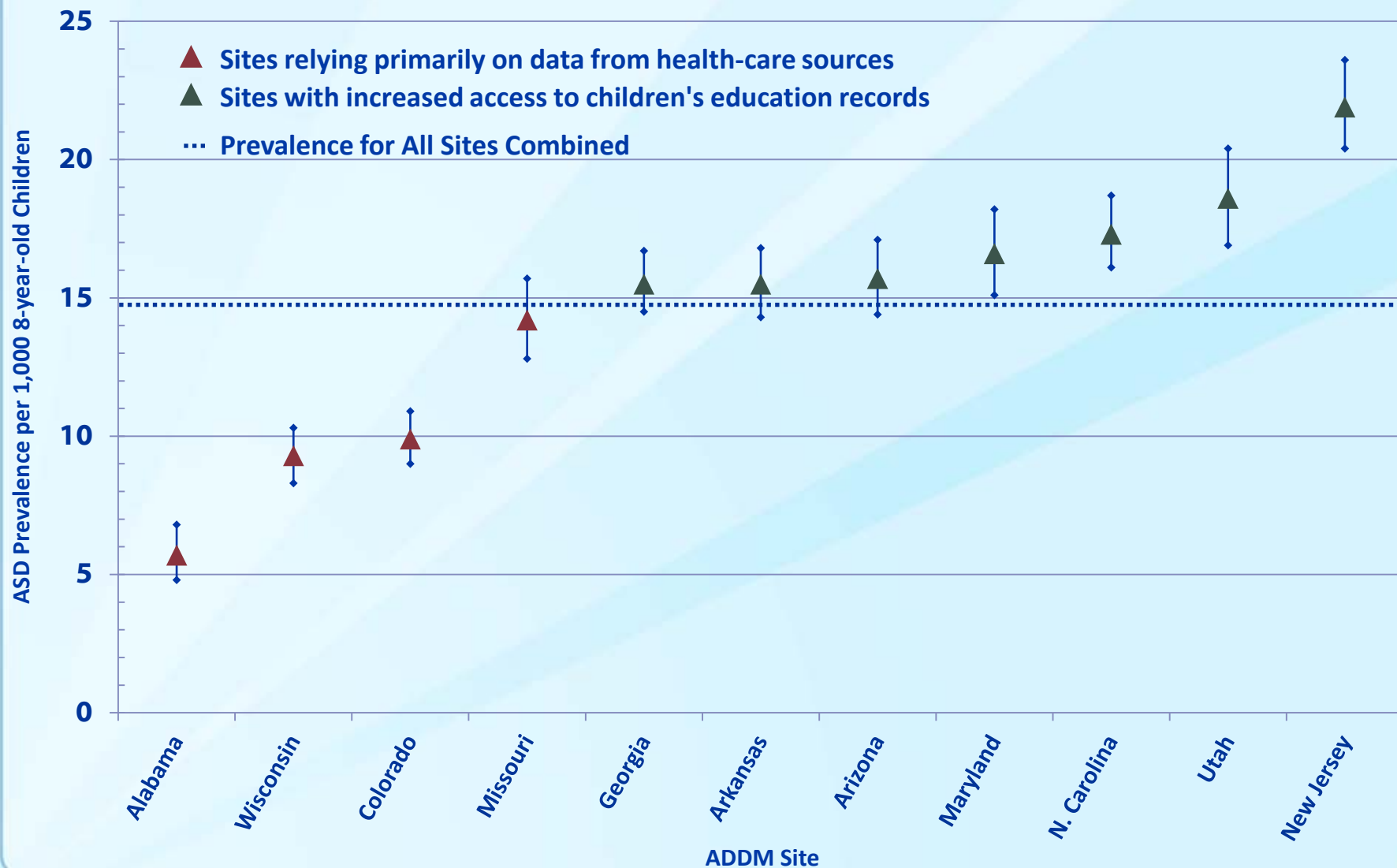
## ADDM 2010 ASD Prevalence among Children aged 8 Years

- Overall ASD prevalence for ADDM 2010 was **14.7** per 1,000 (one in 68) children aged 8 years, based on combined data from 11 sites
- ASD prevalence was **23.7** per 1,000 boys and **5.3** per 1,000 girls (4.5:1 ratio)
- ASD prevalence among white children (**15.8** per 1,000) was significantly greater than that among black (**12.3** per 1,000) and Hispanic children (**10.8** per 1,000)
  - White children were approximately 30% more likely to be identified with ASD than black children and were almost 50% more likely to be identified with ASD than Hispanic children.

## **ADDM 2010 ASD Prevalence among Children aged 8 Years**

- **ASD prevalence estimates varied among sites**  
(from 5.7 to 21.9 per 1,000)
  - Highest prevalence estimates were for New Jersey (21.9), Utah (18.6), North Carolina (17.3), and Maryland (16.6)
  - Three sites between 15–16 per 1,000 (Arizona, Arkansas, Georgia)
  - Four sites with limited or no access to education records (Alabama, Colorado, Missouri, Wisconsin) reported lowest prevalence estimates among all ADDM sites

Variation in estimated prevalence (per 1,000 population) of autism spectrum disorder (ASD) among children aged 8 years — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2010

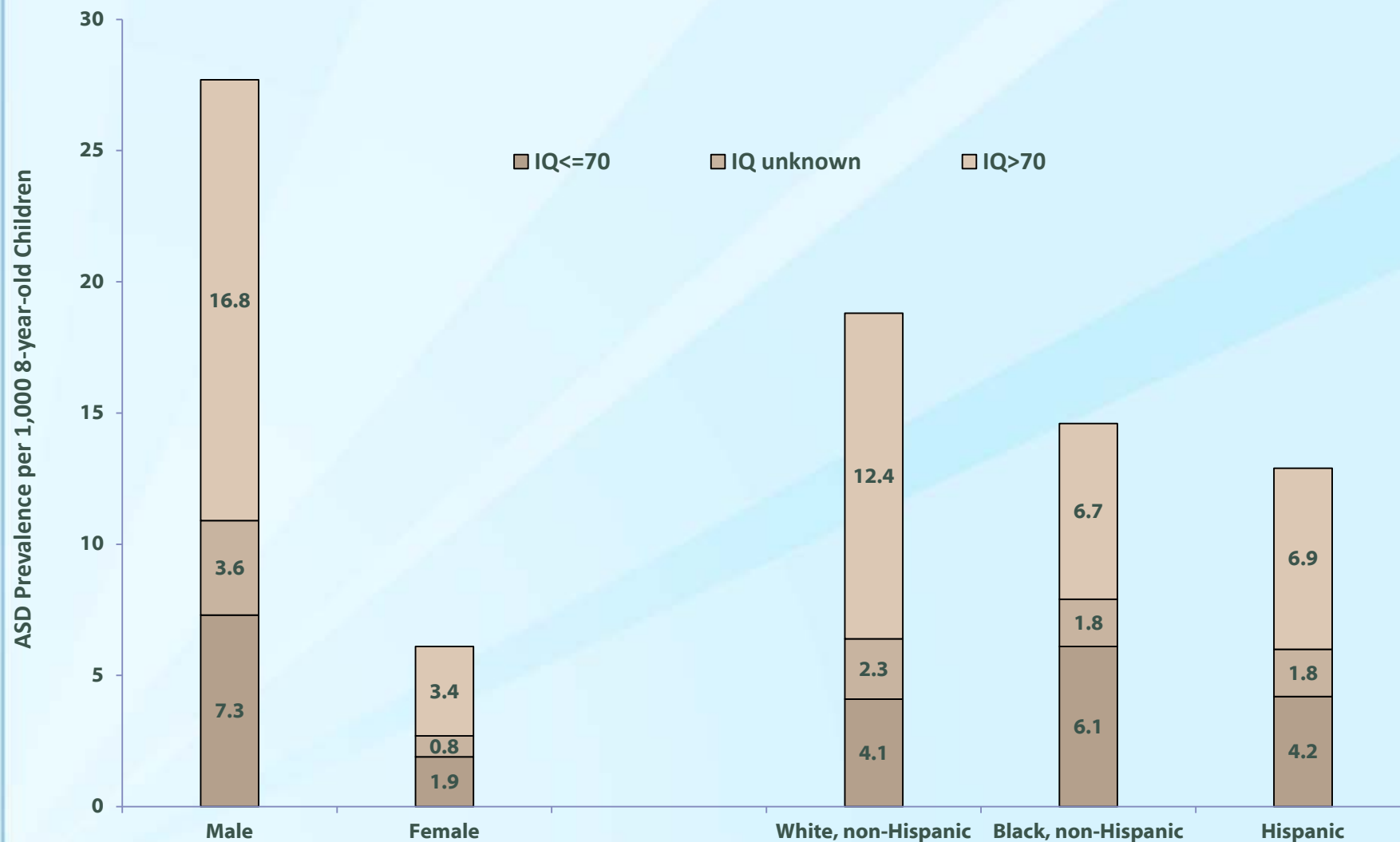


## **ADDM 2010 ASD Prevalence among Children aged 8 Years**

- Among the seven sites with sufficient data on intellectual ability:
  - 31% of children with ASD had IQ scores in the range of intellectual disability (IQ  $\leq 70$ )
  - 23% in the borderline range (IQ = 71–85)
  - 46% in the average or above average range of intellectual ability (IQ  $> 85$ )

# Prevalence of ASD by most recent IQ score and by sex and race/ethnicity — ADDM Network, seven sites\*, 2010

\* Includes sites that had intellectual ability data available for  $\geq 70\%$  of children who met the ASD case definition.



# Earliest Known ASD Diagnosis

## Median Age and Proportion by Diagnostic Subtype

### ADDM Network, 2010

(Combining data from 11 sites reporting for 2010 surveillance year)

Subtype of Earliest Diagnosis:	Autistic Disorder	ASD/PDD	Asperger Disorder
Distribution of Subtypes:	43%	46%	11%
Median Age of Earliest Diagnosis:	48 Months	50 Months	74 Months

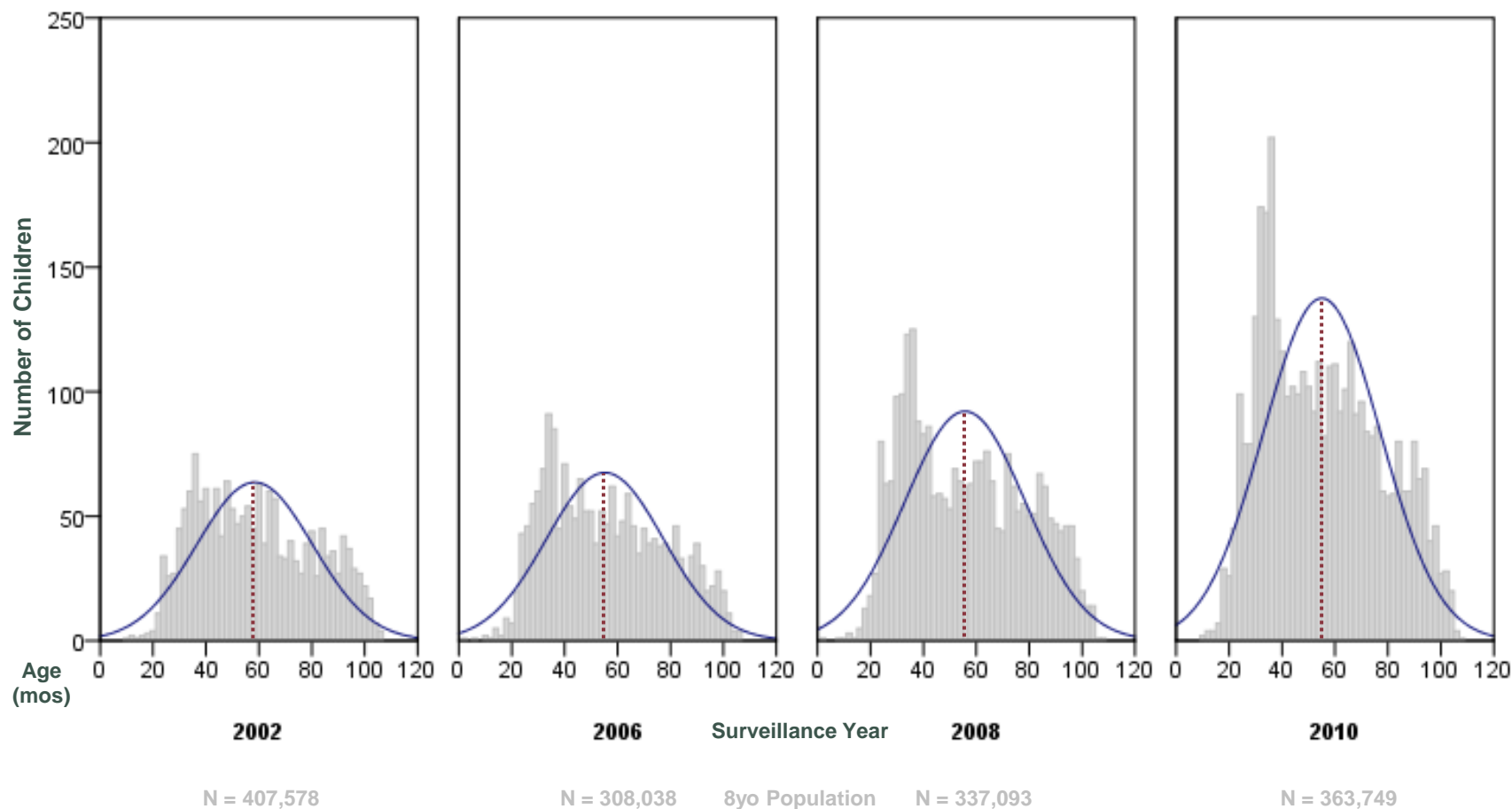
#### Limitations:

- 1) Diagnostic information obtained from evaluation records may not capture the exact age of each child's earliest diagnosis
- 2) Instability of diagnostic subtypes over time



# Age of Earliest Known ASD Diagnosis

## Children Aged 8 Years, ADDM Network, 2002-2010



# Implications of ADDM Network Findings

- ASD continues to be seen as an urgent public health concern
  - Prevalence estimates continue to increase in most ADDM Network communities as well as in other large-scale studies
- Better identification among certain subgroups
  - Still concerned about disparities in prevalence across sites and among children of minority race/ethnicity, low socioeconomic status
- More children than ever are being recognized as having ASD
  - Still concerned that 20% of surveillance-identified children with ASD are not classified with autism by community providers, while for other children ASD is not recognized as early as it can be

# Challenges: Understanding Autism Prevalence

- Wide variation in prevalence estimates across time and space
  - Increased awareness in communities
  - Increased symptoms in population vs. documentation of symptoms
  - Geographic differences in diagnostic practices, program eligibility
  - Changes in policy affecting availability of services
  - No single explanation - multiple factors at play
  - Questions about prevalence among older children and adults
- Changing criteria used to diagnose autism (DSM-IV, DSM-5)
- Limited data on severity of autism symptoms

# ADDM Network Publications (Autism)

1. Retention of autism spectrum diagnoses by community professionals: Findings from the ADDM Network, 2000 and 2006. *Journal of Developmental and Behavioral Pediatrics*. June 2012. Wiggins LD, Baio J, Schieve L, Lee LC, Nicholas J, Rice CE.
2. Prevalence of autism spectrum disorders, ADDM Network, 14 Sites, United States, 2008. *MMWR Surveillance Summaries*. March 2012. CDC.
3. Have secular changes in perinatal risk factors contributed to the recent autism prevalence increase? Development and application of a mathematical assessment model. *Annals of Epidemiology*. October 2011. Schieve LA, Rice C, Devine O, Maenner MJ, Lee LC, Fitzgerald R, Wingate MS, Schendel D, Pettygrove S, Van Naarden Braun K, Durkin M.
4. Racial disparities in community identification of autism spectrum disorders over time; metropolitan Atlanta, Georgia, 2000-2006. *Journal of Developmental and Behavioral Pediatrics*. April 2011. Jarquin VG, Wiggins LD, Schieve LA, Van Naarden-Braun K.
5. Socioeconomic Inequality in the prevalence of autism spectrum disorder: Evidence from a U.S. cross-sectional study. *PLoS ONE*. July 2010. Durkin MS, Maenner MJ, Meaney FJ, Levy SE, DiGuseppi C, Nicholas JS, Kirby RS, Pinto-Martin JA, Schieve LA.
6. Changes in autism spectrum disorder prevalence in 4 areas of the United States. *Disability and Health Journal*, July 2010. Rice CE, Nicholas J, Baio J, Pettygrove S, Lee L, Van Naarden Braun K, Doernberg N, Cunniff C, Newschaffer C, Meaney FJ, Charles J, Washington A, King L, Kolotos M, Mancilla K, Mervis CA, Carpenter L, Yeargin-Allsopp M.
7. Risk for cognitive deficit in a population-based sample of U.S. children with autism spectrum disorders: Variation by perinatal health factors. *Disability and Health Journal*. July 2010. Schieve LA, Baio J, Rice CE, Durkin M, Kirby RS, Drews-Botsch C, Miller LA, Nicholas JS, Cunniff C.
8. Evaluation of a records-review surveillance system used to determine the prevalence of autism spectrum disorders. *Journal of Autism and Developmental Disorders*. June 2010. Avchen R, Wiggins LD, Devine O, Van Naarden-Braun K, Rice C, Hobson N, Schendel D, Yeargin-Allsopp M.
9. Autism spectrum disorders and co-occurring developmental, psychiatric, and medical conditions among children in multiple populations of the United States. *Journal of Developmental & Behavioral Pediatrics*. May 2010. Levy S, Giarelli E, Lee L, Schieve L, Kirby R, Cunniff C, Nicholas J, & Rice C.
10. Sex differences in the evaluation and diagnosis of autism spectrum disorders among children. *Disability and Health Journal*. April 2010. Giarelli E, Wiggins LD, Rice CE, Levy SE, Kirby, RS, Pinto-Martin J, Mandell D.
11. Prevalence of Autism Spectrum Disorders, ADDM Network, United States, 2006. *MMWR Surveillance Summaries*. December 2009. CDC.
12. Brief report: Prevalence of autism spectrum disorders, ADDM Network, United States, 2004. *MMWR Surveillance Summaries*. December 2009. CDC.
13. Developmental regression in children with an autism spectrum disorder identified by a population-based surveillance system. *Autism*. July 2009. Wiggins LD, Rice CE, Baio J.
14. Timing of identification among children with an autism spectrum disorder: Findings from a population-based surveillance study. *Journal of the American Academy of Child and Adolescent Psychiatry*. May 2009. Shattuck PT, et al.
15. Racial and ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health*. March 2009. Mandell D, Wiggins L, Carpenter L, Daniels J, DiGuseppi C, Durkin M, Giarelli E, Morrier M, Nichols J, Pinto-Martin J, Shattuck P, Thomas K, Yeargin-Allsopp M, Kirby R.
16. Advanced Parental Age and the Risk of Autism Spectrum Disorder. *American Journal of Epidemiology*. December 2008. Durkin MS, Maenner MJ, Newschaffer CJ, Lee LC, Cunniff CM, Daniels JL, Kirby RS, Leavitt L, Miller L, Zahorodny W, Schieve LA.
17. Relationships between multiple births and autism spectrum disorders, cerebral palsy, and intellectual disabilities: ADDM Network - 2002 Surveillance Year. *Autism Research*. October 2008. Van Naarden Braun K, Schieve L, Daniels J, Durkin M, Giarelli E, Kirby RS, Lee LC, Newschaffer C, Nicholas J, Pinto-Martin J.
18. A Public Health Collaboration for the Surveillance of Autism Spectrum Disorders. *Paediatric and Perinatal Epidemiology*. March 2007. Rice C, Baio J, Van Naarden Braun K, Doernberg N, Meaney FJ, Kirby R, for the ADDM Network.
19. Prevalence of autism spectrum disorders, ADDM Network, six sites, United States, 2000. *MMWR Surveillance Summaries*. February 2007. CDC.
20. Prevalence of autism spectrum disorders, ADDM Network, 14 Sites, United States, 2002. *MMWR Surveillance Summaries*. February 2007. CDC.
21. Evaluation of a methodology for a collaborative multiple source surveillance network for autism spectrum disorders, ADDM Network, 14 sites, United States, 2002. *MMWR Surveillance Summaries*. February 2007. Van Naarden Braun K, et al.
22. Examination of the Time Between First Evaluation and First Autism Spectrum Diagnosis in a Population-Based Sample. *Journal of Developmental and Behavioral Pediatrics*. April 2006. Wiggins LD, Baio J, Rice C.

# Moving Forward

- Continue ongoing surveillance to evaluate temporal trends
- Investigator-initiated analyses
  - Timing and stability of diagnosis
  - Incorporating DSM-5 criteria
  - Socioeconomic disparities
  - Intellectual functioning
  - Geospatial analyses
  - Birth characteristics
    - Parental age
    - Multiple births
    - Gestational age and birthweight

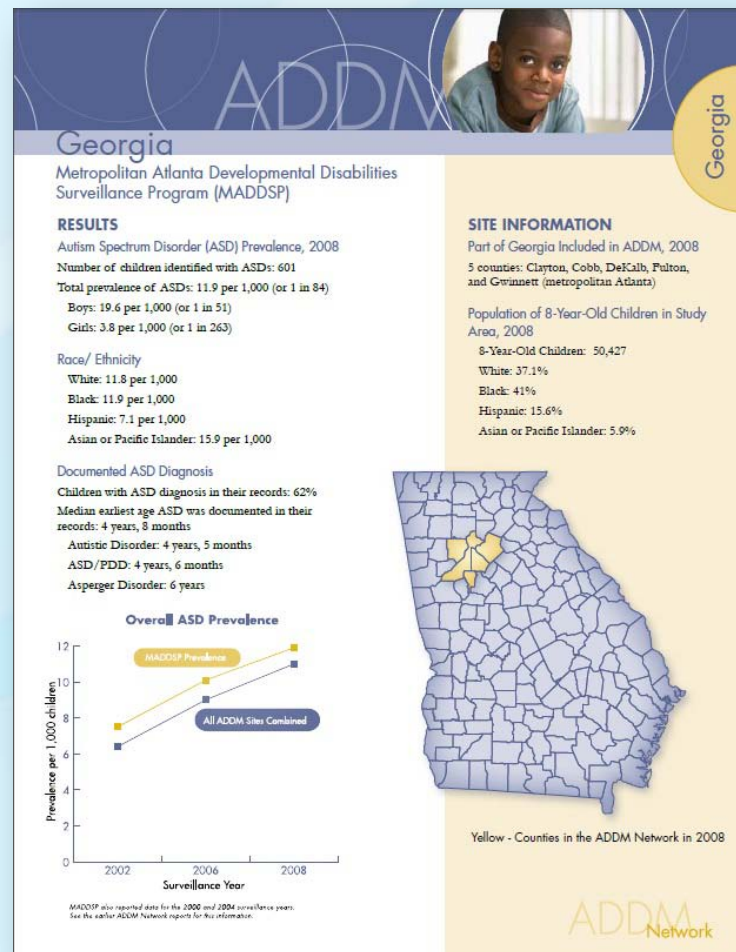
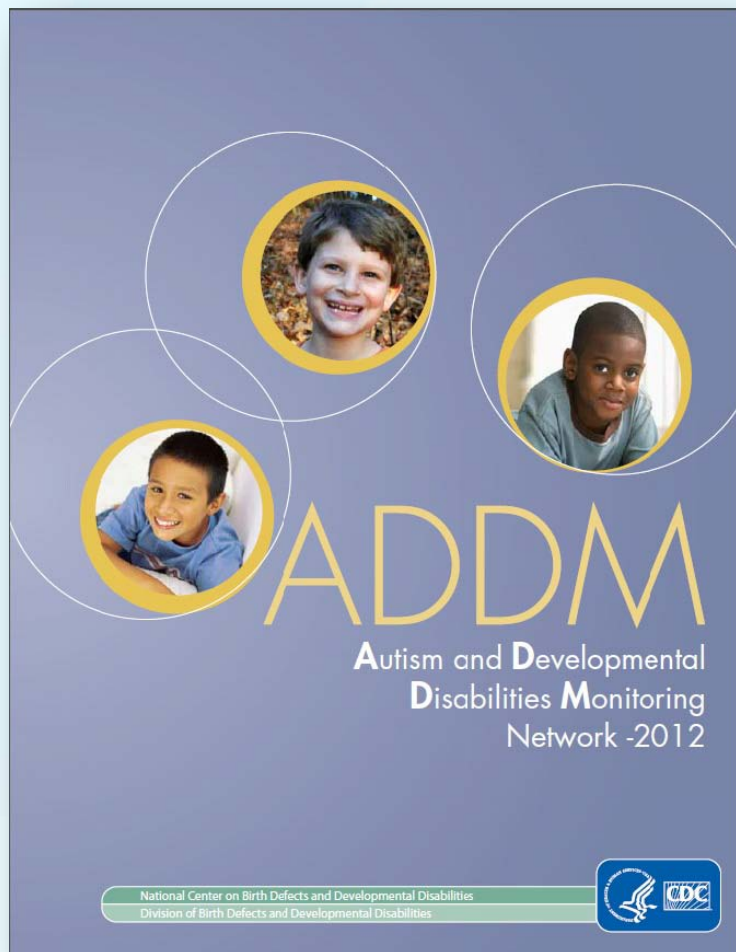


# Acknowledgments

Martha Wingate, PhD, University of Alabama at Birmingham; Russell S. Kirby, PhD, University of South Florida, Tampa; Sydney Pettygrove, PhD, Chris Cuniff, MD, University of Arizona, Tucson; Eldon Schulz, MD, University of Arkansas for Medical Sciences, Little Rock; Tista Ghosh, MD, Colorado Department of Public Health and Environment, Denver; Cordelia Robinson, PhD, University of Colorado at Denver and Health Sciences Center; Li-Ching Lee, PhD, Johns Hopkins University, Rebecca Landa, PhD, Kennedy Krieger Institute, Baltimore, Maryland; John Constantino, MD, Robert Fitzgerald, PhD, Washington University in St. Louis, Missouri; Walter Zahorodny, PhD, Rutgers University New Jersey Medical School, Newark; Julie Daniels, PhD, University of North Carolina, Chapel Hill; Joyce Nicholas, PhD, Jane Charles, MD, Medical University of South Carolina, Charleston; William McMahon, MD, Deborah Bilder, MD, University of Utah, Salt Lake City; Maureen Durkin, PhD, DrPH, University of Wisconsin, Madison; Jon Baio, EdS, Deborah Christensen, PhD, Kim Van Naarden Braun, PhD, Heather Clayton, PhD, Alyson Goodman, MD, Nancy Doernberg, Marshalyne Yeargin-Allsopp, MD, Division of Birth Defects and Developmental Disabilities, National Center on Birth Defects and Developmental Disabilities, CDC. Data collection was coordinated at each site by ADDM Network project coordinators: Eric Lott, University of Alabama at Birmingham; Kristen Clancy Mancilla, University of Arizona, Tucson; Allison Hudson, University of Arkansas for Medical Sciences, Little Rock; Kelly Kast, MSPH, Colorado Department of Public Health and Environment, Denver; Kwinettaion Jolly, MS, Research Triangle Institute, Atlanta, Georgia; Ann Chang, Rebecca Harrington, PhD, Johns Hopkins University, Baltimore, Maryland; Rob Fitzgerald, MPH, Washington University, St. Louis, Missouri; Josephine Shenouda, MS, Rutgers New Jersey Medical School, Newark; Paula Bell, University of North Carolina, Chapel Hill; Colin Kingsbury, MS, Amanda Bakian, PhD, Amy Henderson, University of Utah, Salt Lake City; Carrie Arneson, MS, University of Wisconsin, Madison; Anita Washington, MPH, Gal Frenkel, MPH, Division of Birth Defects and Developmental Disabilities, National Center on Birth Defects and Developmental Disabilities, CDC. Additional assistance was provided by project staff including data abstractors, clinician reviewers, epidemiologists, and data management/programming support. Ongoing ADDM Network support was provided by Victoria Wright, National Center on Birth Defects and Developmental Disabilities, CDC.



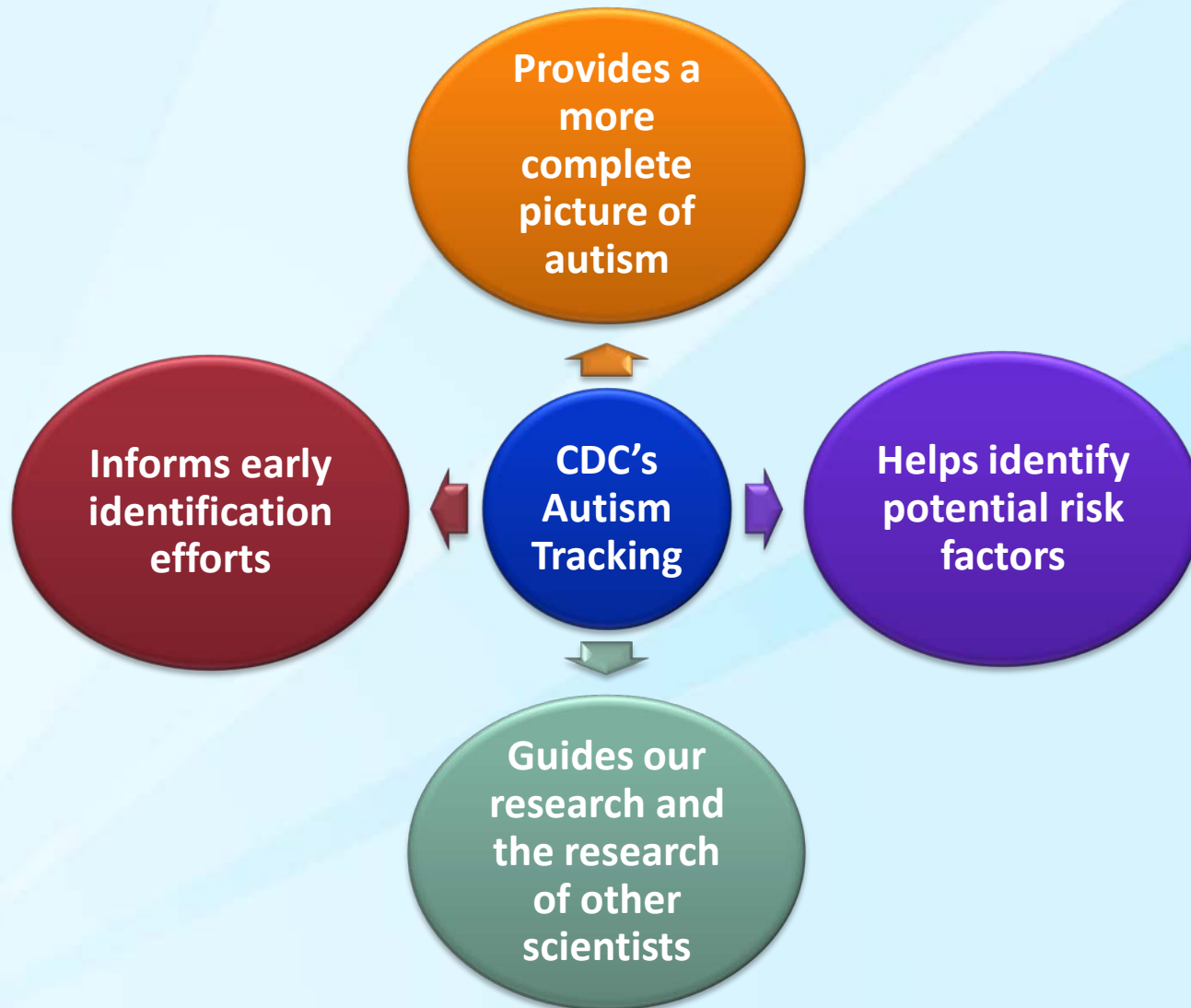
# Community Report on Autism



To download a copy of the Community Report, please visit [www.cdc.gov/autism](http://www.cdc.gov/autism)



## More Than Just A Number...



# CDC's Autism Public Health Actions

- Surveillance:
  - Autism and Developmental Disabilities Monitoring (ADDM) Network
    - Document and understand changes in ASD prevalence over time
    - Expand monitoring to include younger populations
- Research:
  - Study to Explore Early Development (SEED)
    - Identify factors that may put children at risk for ASD
- Awareness:
  - *Learn the Signs. Act Early.*
    - Improve early identification of developmental delays and ASD
- Collaboration:
  - Interagency Autism Coordinating Committee (IACC)
    - Public/Private coordination of research efforts to address ASD

# Meeting of the IACC

---

## Birth to 5: Watch Me Thrive

**Linda K. Smith**

Deputy Assistant Secretary and Inter-Department Liaison  
Early Childhood Development  
U.S. Department of Health and Human Services  
Administration for Children and Families (ACF)

# Birth to Five: Watch Me Thrive!

Developmental and Behavioral Screening and Support

Office of the Deputy Assistant Secretary for  
Early Childhood

Administration for Children and Families

U.S. Department of Health and Human Services

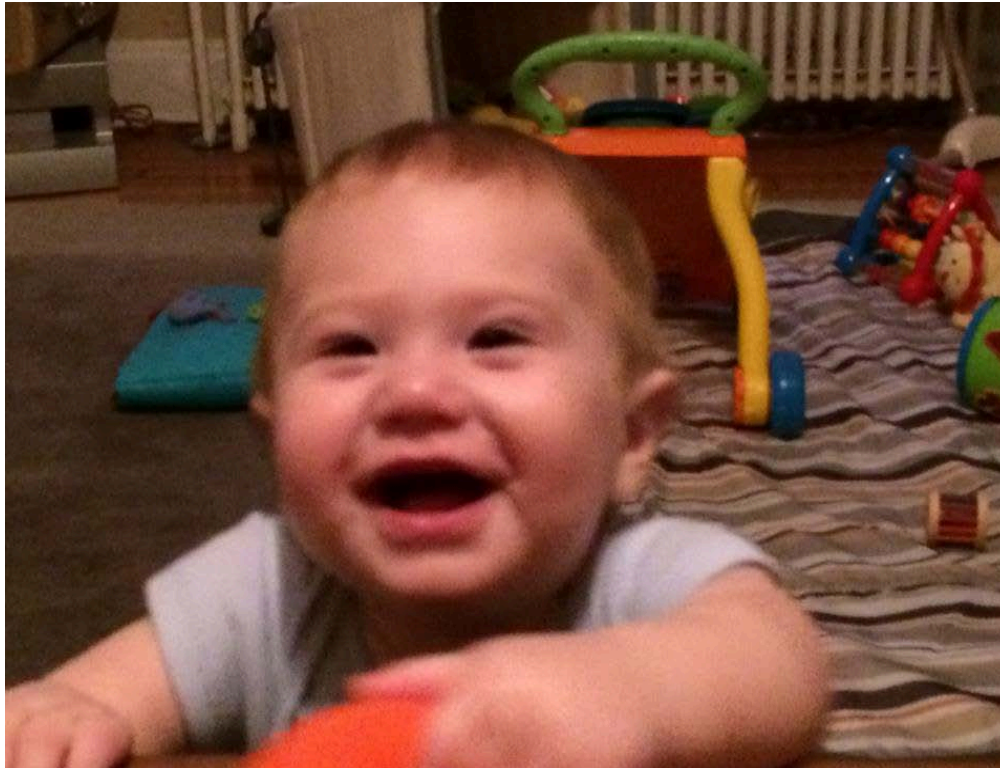


# The Issue

- **1 in 4 children**, age 0-5 years, are at moderate or high risk for developmental, behavioral, or social delay
- AAP recommends screening of all children for developmental, behavioral, and social delays at 9, 18, and 24 or 30 months
- Less than 50% of pediatricians use valid and reliable screening tools
- Pediatricians cannot do it alone— a coordinated system of care is needed to achieve universal developmental and behavioral screening and support



Making sure all of our youngest children are screened and given support *early* are important priorities for the U.S. Departments of Health and Human Services and Education.



Public awareness of child development and the importance of families is critical.





## Birth to Five: Watch Me Thrive!







# The Partners

- Administration for Children and Families
- Administration for Community Living
- Centers for Disease Control and Prevention
- Centers for Medicare and Medicaid Services
- Health Resources and Services Administration
- National Institute for Child Health and Human Development
- Substance Abuse and Mental Health Services Administration
- Office of Special Education Programs, Department of Education

# *Birth to Five: Watch Me Thrive! Strategy*

- Coordinated public outreach campaign to promote awareness of child development and developmental and behavioral screening, referral, and follow-up.
- Key messages of the campaign include:
  - Celebrating developmental milestones
  - Implementing universal developmental and behavioral screening and support
  - Improving early detection
  - Enhancing developmental supports



# *Birth to Five: Watch Me Thrive!*

*Birth to Five: Watch Me Thrive* consists of three components:

1. **A compendium** that reviews implementation, reliability and validity characteristics of screening instruments;
2. **User guides**, designed for providers from multiple sectors as well as the communities in which they live, to assist in selecting screening instruments;
3. ***Birth to Five: Watch Me Thrive! Toolkit***, a collection of resources to bring awareness to parents and providers about child development, screening, and where to find services and supports locally if a concern exists.

# *Birth to Five: Watch Me Thrive!*

## *Compendium*

- First line screening instruments for children, birth to 5 years
- Includes a series “at a glance” tables and individual profiles for each tool.
- Information such as cost, administration time, evidence quality level, training required, languages available, subpopulations in which tools have been validated, and age range covered, is include.
- Can be used by early care and education providers, pediatricians, medical providers, home visitors, child welfare case workers, mental or behavioral health professionals, early intervention specialists, and various others professionals that serve young children and families

# *Birth to Five: Watch Me Thrive!*

## *Compendium*

- **Compendium Inclusion Criteria:**
  - Designed for the purpose of screening (not child assessment).
  - Appropriate for use with children between birth and age five.
  - Cover multiple developmental domains (i.e. physical/motor, cognitive, language/communication, social-emotional development).
  - Available for use by early childhood professionals
  - Include family input
  - High quality psychometrics: Sensitivity and specificity of 0.7 or greater

# *Birth to Five: Watch Me Thrive!*

## *User Guides*

Designed to accompany the compendium of tools and include information on:

- Developmental milestones
- Screening, monitoring and surveillance
- How to engage families in the process
- How and where to refer if concerns are detected
- How to choose the appropriate tool to fit the need



# *Birth to Five: Watch Me Thrive!*

## *User Guides*

- Guides included consistent messaging and themes, but were individually tailored for use across various sectors and professionals. Guides were developed for:
  - Early childhood teachers
  - Home visitors
  - Primary care providers
  - Behavioral health providers
  - Child welfare case workers
  - Housing and homeless shelter providers
  - Local and community-level policy makers





# *Birth to Five: Watch Me Thrive!*

## *Family Screening Passport*

- Akin to an immunization card, the screening passport helps families keep track of their child's screening history.
- Encourages families to share their child's screening results with their child's doctor and other service providers who work with or care for the child, such as child care providers and early interventionists.
- Intended to reduce duplication in screenings and promote a “system of care”.



# *Birth to Five: Watch Me Thrive!*

## *Toolkit*

- The electronic *Watch Me Thrive Toolkit* include a collection of Federal resources to bring awareness to multiple audiences about child development, including:
  - Information on developmental milestones
  - Milestone checklists and tracking tools
  - Tips for caregivers to promote healthy development
  - Guidance for finding help locally
  - Fact sheets on specific developmental disabilities or delays
  - Learning modules for a variety of providers



# *Birth to Five: Watch Me Thrive!*

## *Evaluation*

- CDC is leading the evaluation effort and a comprehensive plan to measure impact is under development;
- Each partner agency is measuring dissemination reach through their technical assistance networks and stakeholders;
- Web analytics;
- The *Help Me Grow Network* is tracking change in referral numbers;
- Track screening numbers in large national data sets (e.g. National Survey of Children with Special Healthcare Needs)



# Questions?

**Birth to 5: Watch Me Thrive!**  
**[www.hhs.gov/watchmethrive](http://www.hhs.gov/watchmethrive)**

# Meeting of the IACC

---

## Morning Agenda - continued

**10:15 AM      Break**

**10:30            The BRAIN Initiative**

**Story Landis, Ph.D.**

Director

National Institute of Neurological Disorders  
and Stroke (NINDS)

**10:50            Congressionally Directed Medical  
Research Programs (CDMRP)**

**Donna Kimbark, Ph.D.**

Program Manager

U.S. Department of Defense (DoD)

# Meeting of the IACC

---

# Break

# Meeting of the IACC

---

## The BRAIN Initiative

**Story Landis, Ph.D.**

Director

National Institute of Neurological Disorders and Stroke (NINDS)

# NIH and the BRAIN Initiative

*Brain Research through Advancing Innovative  
Neurotechnologies*

IACC

Story Landis

April 8, 2014



# “The Next Great American Project”



## *Learning the Language of the Brain*

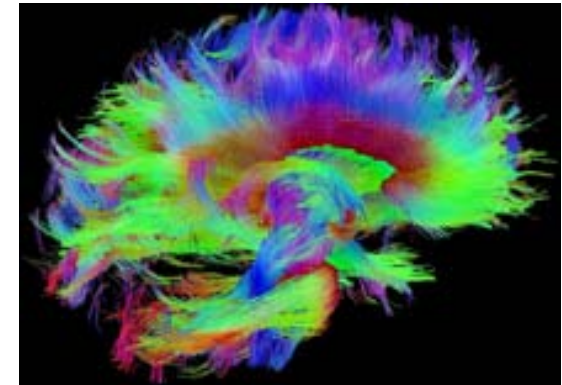
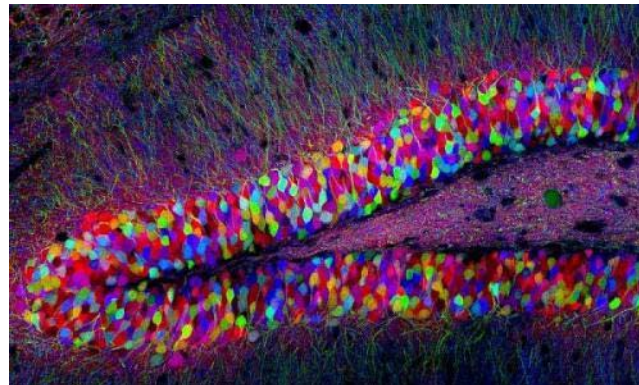
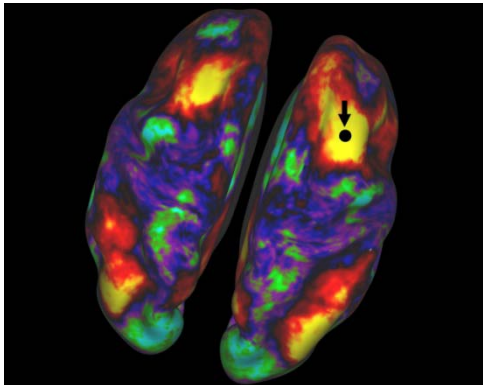
# The Vision



“So there is this enormous mystery waiting to be unlocked, and the BRAIN Initiative will change that by **giving scientists the tools they need to get a dynamic picture of the brain in action** and better understand how we think and how we learn and how we remember. And that knowledge could be – will be – transformative.”

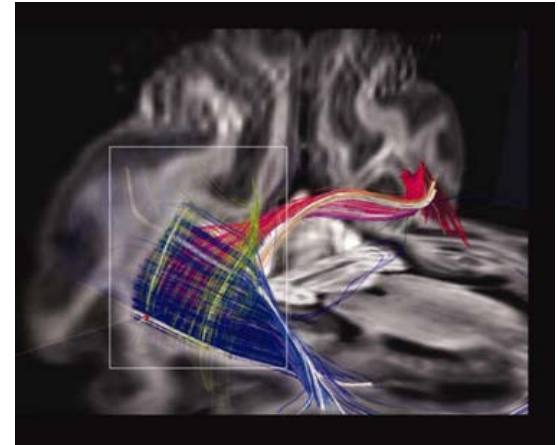
# Brain Disorders Affect Us All

- **Neurodegenerative disorders**
  - Alzheimer's, Parkinson's, ALS, Huntington's...
  - Annual cost of dementia care in the U.S. is ~200 billion
- **Cognitive and affective disorders**
  - Schizophrenia, Bipolar Disorder, Depression, Anxiety, OCD...
- **Neurodevelopmental disorders**
  - Autism, Attention-deficit disorder, Epilepsy, Intellectual disability...
- **Injury- and insult-induced disorders**
  - PTSD, Traumatic brain injury, Stroke...



# The Science Is Ready

- Progress in neuroscience is yielding new insights into brain structure and function

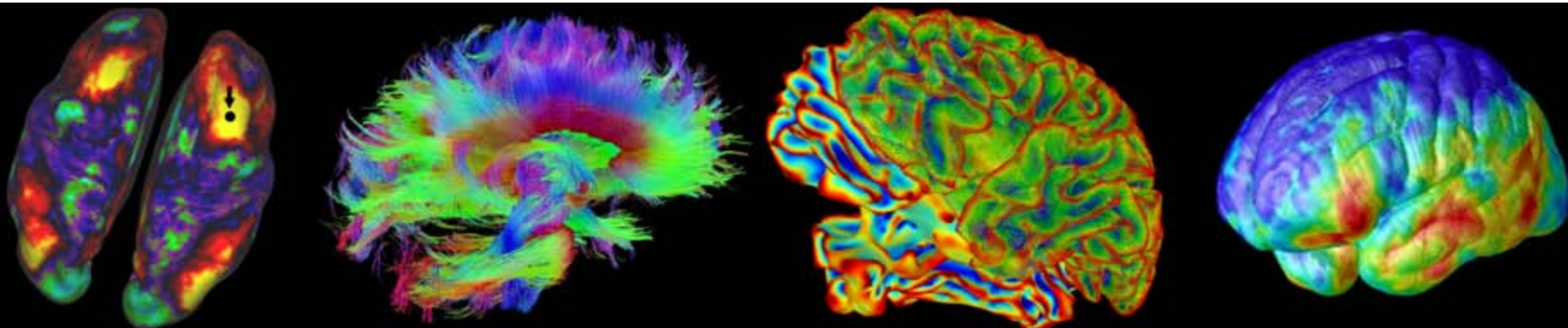


- Progress in optics, genetics, nanotechnology, informatics, etc. is rapidly advancing the design of new tools



# BRAIN Initiative: *Approach*

- Accelerate development, application of innovative technologies to construct dynamic picture of brain function that integrates neuronal and circuit activity over time and space
- Build on growing scientific foundation – neuroscience, genetics, physics, engineering, informatics, nanoscience, chemistry, mathematics, etc. – to catalyze interdisciplinary effort of unprecedented scope
- Pursue experiments in simpler model systems and in humans.



# NIH BRAIN: *How will it work?*

- NIH BRAIN Working Group is developing a research plan
  - Articulate scientific goals for NIH research under BRAIN
    - Identified high-priority areas for FY14 funding in Sept '13
    - NIH issued 6 Requests For Applications in Dec '13
    - Applications due by end of March, reviewed in the summer and funded in Sept. '14
    - A final plan that includes timetables, milestones, and costs is due June '14

# NIH BRAIN Working Group: *Members*

**Cornelia Bargmann**, Rockefeller  
(*co-chair*)

**William Newsome**, Stanford  
(*co-chair*)

**David Anderson**, Caltech

**Emery Brown**, MIT

**Karl Deisseroth**, Stanford

**John Donoghue**, Brown

**Peter MacLeish**, Morehouse

**Eve Marder**, Brandeis

**Richard Normann**, Utah

**Joshua Sanes**, Harvard

**Mark Schnitzer**, Stanford

**Terrence Sejnowski**, Salk

**David Tank**, Princeton

**Roger Tsien**, UCSD

**Kamil Ugurbil**, Minnesota

## *EX OFFICIO MEMBERS*

**Kathy Hudson**, NIH

**Geoffrey Ling**, DARPA

**Carlos Pena**, FDA

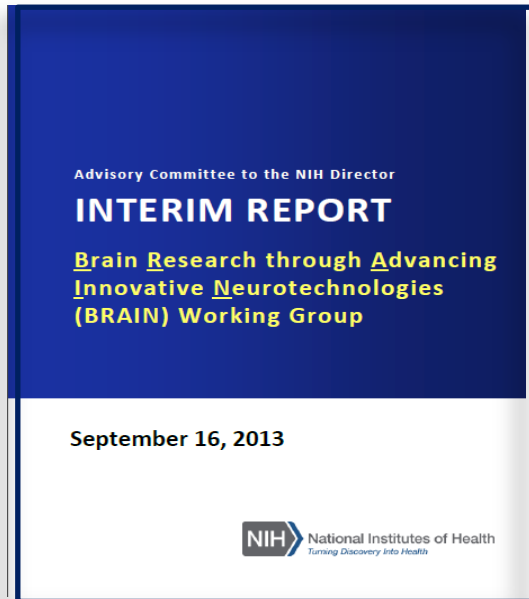
**John Wingfield**, NSF

## *EXECUTIVE SECRETARY*

**Lyric Jorgenson**, NIH



# NIH BRAIN Working Group: *High Priority Research Areas*



- 1) Generate a census of cell types
- 2) Create structural maps of the brain
- 3) Develop new large-scale network recording capabilities
- 4) Develop a suite of tools for circuit manipulation
- 5) Link neuronal activity to behavior
- 6) Integrate theory, modeling, statistics, and computation with experimentation
- 7) Delineate mechanisms underlying human imaging technologies
- 8) Create mechanisms to enable collection of human data
- 9) Disseminate knowledge and training

# NIH RFAs: *Cells, circuits, human imaging*



1. Transformative Approaches for Cell-Type Classification in the Brain (*addresses WG rec 1*)
  - Create classification strategies to generate a systematic inventory/census of cell types in the brain using existing tools and technologies
3. New Technologies and Novel Approaches for Large-Scale Recording and Modulation in the Nervous System (*addresses WG rec 3, 4, & 5*)
  - Focuses on the development and proof-of-concept testing of new technologies for large scale recording and manipulation of neural activity
6. Planning for Next Generation Human Imaging (*addresses WG rec 7*)
  - Aims to create teams of scientists to plan for a new generation of non-invasive imaging techniques that will be used to understand human brain function





# Plans from Other Agencies: **DARPA**

- System-Based Neurotechnology for Emerging Therapies (SUBNETS)
  - Create closed-loop medical devices able to measure and modulate networks of neurons in cases of intractable psychiatric illness and alleviate severe symptoms of diseases
- Restoring Active Memory (RAM)
  - Deliver a wireless device that repairs brain damage and restores memory loss
- Prosthetic Hand Proprioception and Touch Interfaces (HAPTIX)
  - Develop human-ready implantable electronic microsystems that enable amputees to intuitively control and gain sensory functions with prosthetic limbs

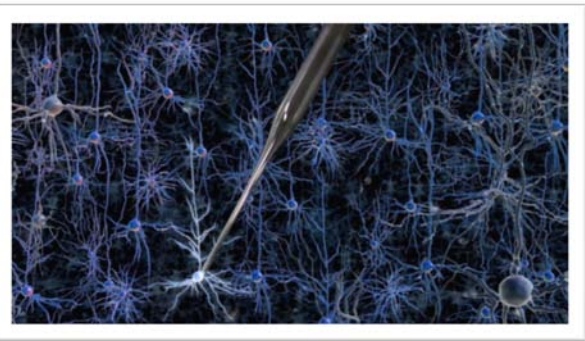




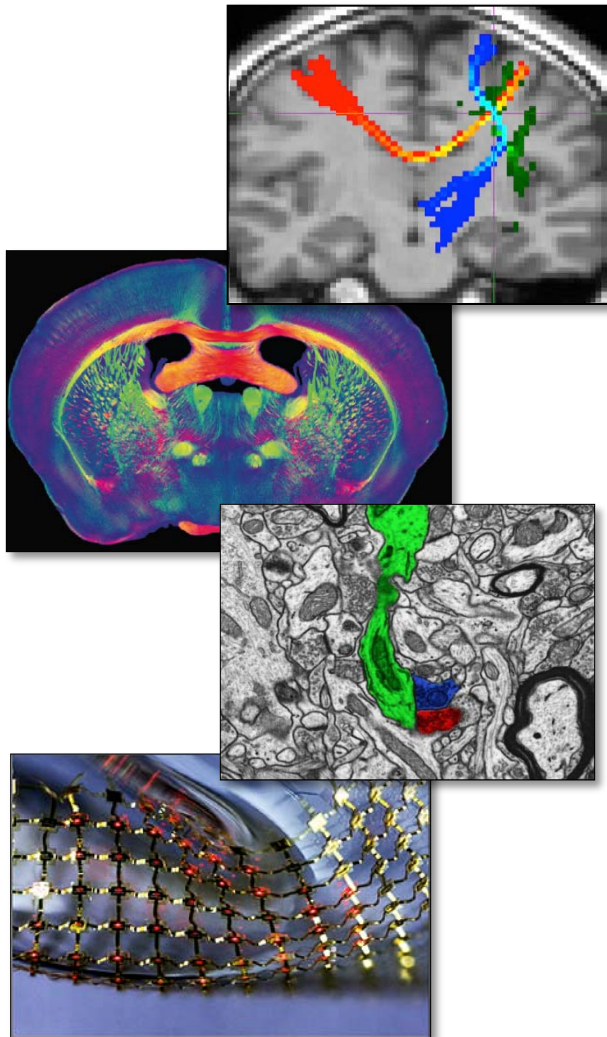
# Plans from Other Agencies: NSF



- Meetings, organized by different Directorates, similar in scope to NIH-sponsored meetings
- Examples NSF investments in The BRAIN Initiative include:
  - \$25 million Science and Technology Center on “Brains, Minds and Machines”
  - Research Coordination Networks (RCNs) to organize the scientific community and increase collaboration



# BRAIN Initiative: High Impact/High Quality Science



## The BRAIN Initiative<sup>SM</sup> must accelerate other areas of neuroscience research

- NIH spends ~\$5.5B/year on neuroscience research. BRAIN will be \$40M (<1%) in 2014. It must focus, yet have broad impact
- Emphasis: tools to enhance **many** areas of brain research and methods for deeper understanding of **all** brain disorders

## Technology is not an end in itself

- Focus is on **acquiring fundamental insight** about nervous system function in health and disease. What tools and infrastructure are needed?

## Pose the problems, don't dictate the solutions

- Allow the most compelling ideas to flourish – it is early and new approaches are still emerging. Encourage collaboration.



# Public Interest in BRAIN is Growing



# Meeting of the IACC

---

## Congressionally Directed Medical Research Programs

**Donna Kimbark, Ph.D.**

Program Manager

Autism Research Program

Congressionally Directed Medical Research Programs (CDMRP)

U.S. Department of Defense (DoD)



# The Congressionally Directed Medical Research Programs: Autism Research Program

Donna M. Kimbark, Ph.D.  
Program Manager



The views expressed in this presentation are those of the author and may not reflect the official policy or position of the Department of the Army, Department of Defense, or the U.S. Government.



*US Army Medical Research and Materiel Command*



# Who is the CDMRP?



DEPARTMENT OF  
DEFENSE



DEPARTMENT  
OF THE ARMY



**ARMY MEDICINE**  
Serving To Heal...Honored To Serve

ARMY  
MEDICAL  
COMMAND



MEDICAL  
RESEARCH  
AND  
MATERIEL  
COMMAND



CONGRESSIONALLY  
DIRECTED MEDICAL  
RESEARCH  
PROGRAMS



*US Army Medical Research and Materiel Command*



# CDMRP Partnerships

## Advocates

- ❖ Demonstrate need
- ❖ Participate at all levels
- ❖ Passion and perspective



## Congress

- ❖ Add funds to budget
- ❖ Targeted guidance
- ❖ Opportunity to leverage



IMPROVE  
HEALTH  
(CURE)

## Researchers

- ❖ Innovation and gaps
- ❖ Risk/Benefit
- ❖ Product-oriented



## DOD

- ❖ Program management
- ❖ Regulatory and budget requirements
- ❖ Institute of Medicine model

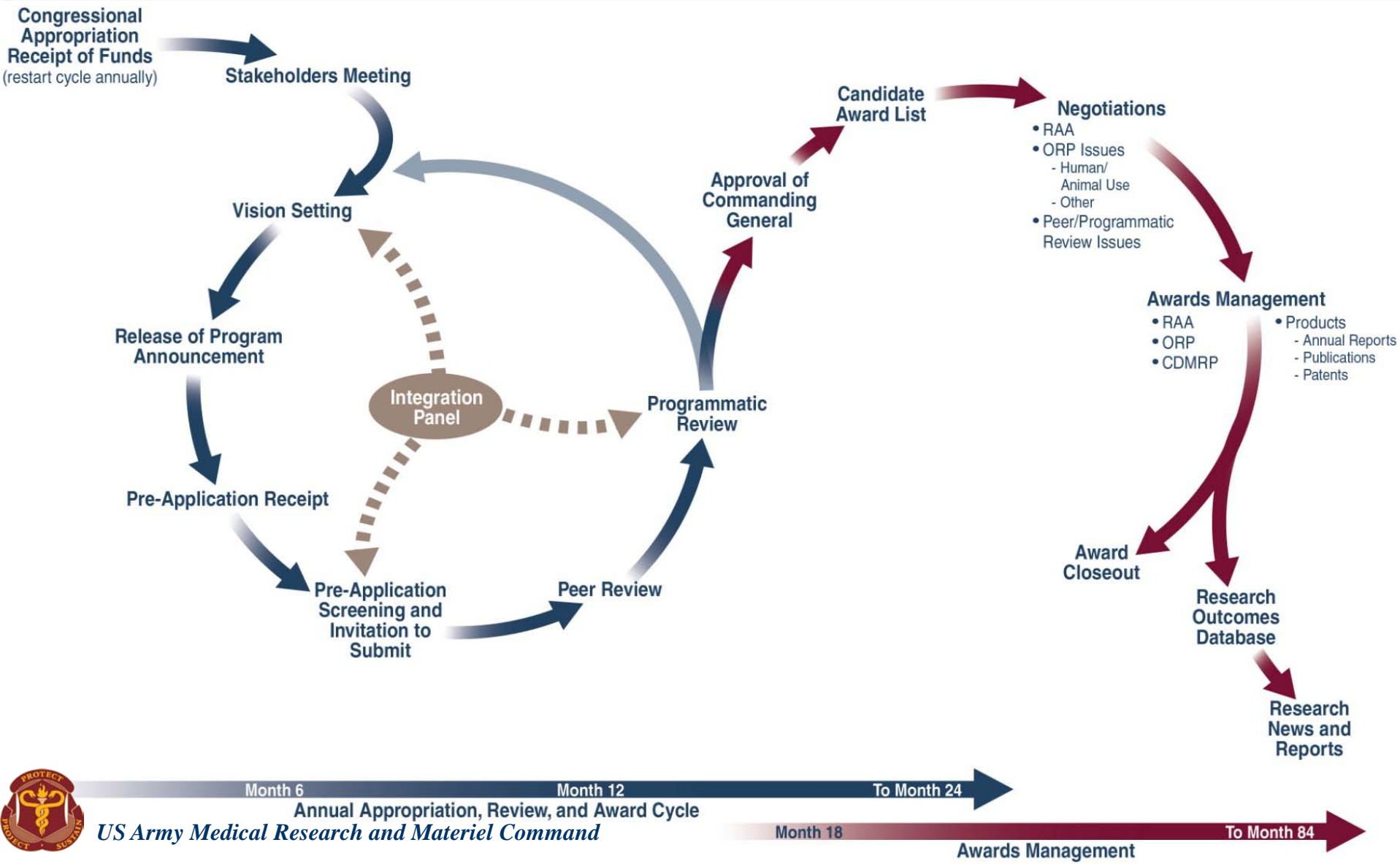


# Hallmarks of the CDMRP

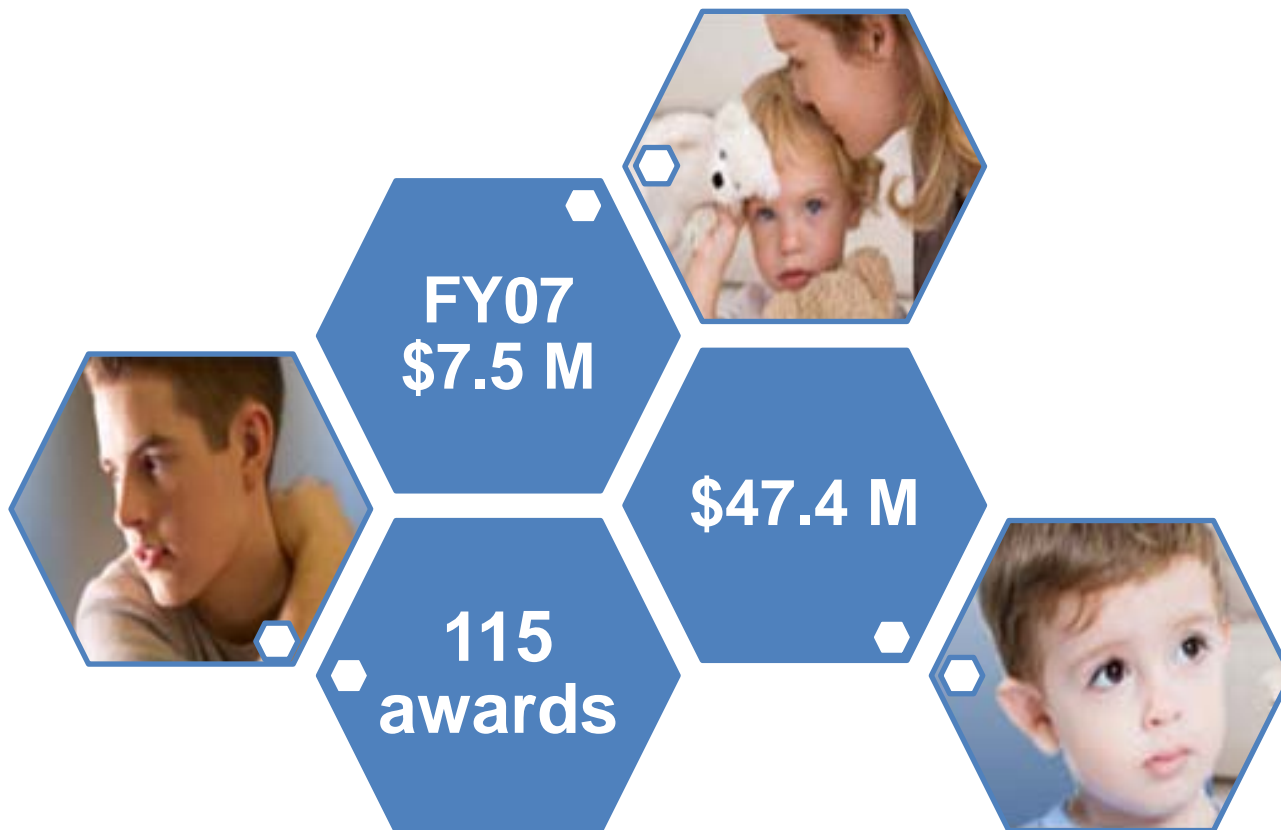
- Research funds added to DOD budget by Congress
- Vision is adapted yearly, and award mechanisms are changed as needed
- Advocates participate throughout process
- Fund highly innovative, high-impact research
- Fund nationally and internationally
- Two-tier formal review of applications – Institute of Medicine model



# Program Execution



# History and Background





# FY14 ARP Integration Panel Members

- Craig Powell, M.D., Ph.D, Chair  
University of Texas Southwestern  
Medical Center
- David Bellinger, Ph.D.  
Harvard School of Public Health,  
Children's Hospital Boston
- Daniel Campbell, Ph.D.  
University of Southern California
- Katarzyna Chawarska, Ph.D.  
Yale University
- Diane Chugani, Ph.D.  
Wayne State University;  
Children's Hospital of Michigan
- Julie Daniels, Ph.D.  
University of North Carolina
- John Davison III, MBA, Ph.D.  
Defense Health Agency
- Ann Gibbons, J.D.  
Autism Speaks
- Nancy Minshew, M.D.  
University of Pittsburgh
- Shelley Reynolds, B.A.  
Unlocking Autism
- Col Cherri Shireman  
US Air Force Medical Support  
Agency
- Christopher Stodgell, Ph.D.  
University of Rochester
- Robert Vogt, Jr., Ph.D.  
Centers for Disease Control and  
Prevention





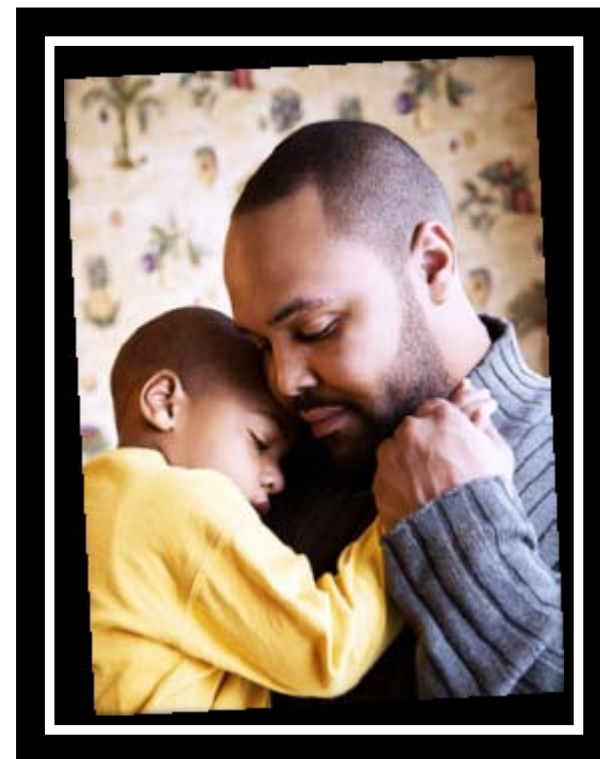
# Vision and Mission

## Vision

Improve the lives of individuals with autism spectrum disorder now

## Mission

Promote innovative research that advances the understanding of autism spectrum disorder and leads to improved outcomes



# Mechanisms toward the ARP Vision

*Improve the lives of individuals with autism spectrum disorder now*

*As a research funding agency how do we do this?*



# FY14 Areas of Interest

## Clinical Trial Award

- Behavioral and other non-pharmacological therapies
- Pharmacological treatments in autism or well-defined subgroups of autism (e.g., genetic, phenotypic, co-occurring conditions)
- Dissemination/Implementation of established, efficacious behavioral interventions
- Therapies to alleviate conditions co-occurring with ASD (e.g., sleep disturbances, gastrointestinal issues, aggression, depression, anxiety)

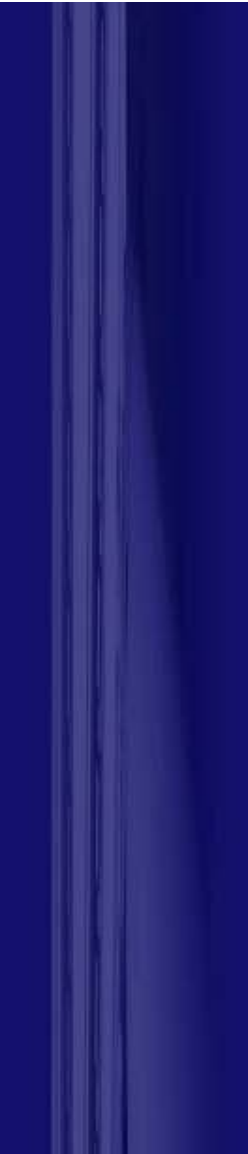


# FY14 Areas of Interest

## Idea Development Award

- Environmental risk factors
- Mechanisms of heterogeneous clinical expression or response to treatment of ASD, excluding new gene discovery
- Mechanisms underlying conditions co-occurring with ASD (e.g., sleep disturbances, gastrointestinal issues, aggression, depression, anxiety)
- Novel therapeutics using valid preclinical models
- Psychosocial factors promoting success in key transitions to independence for individuals living with ASD

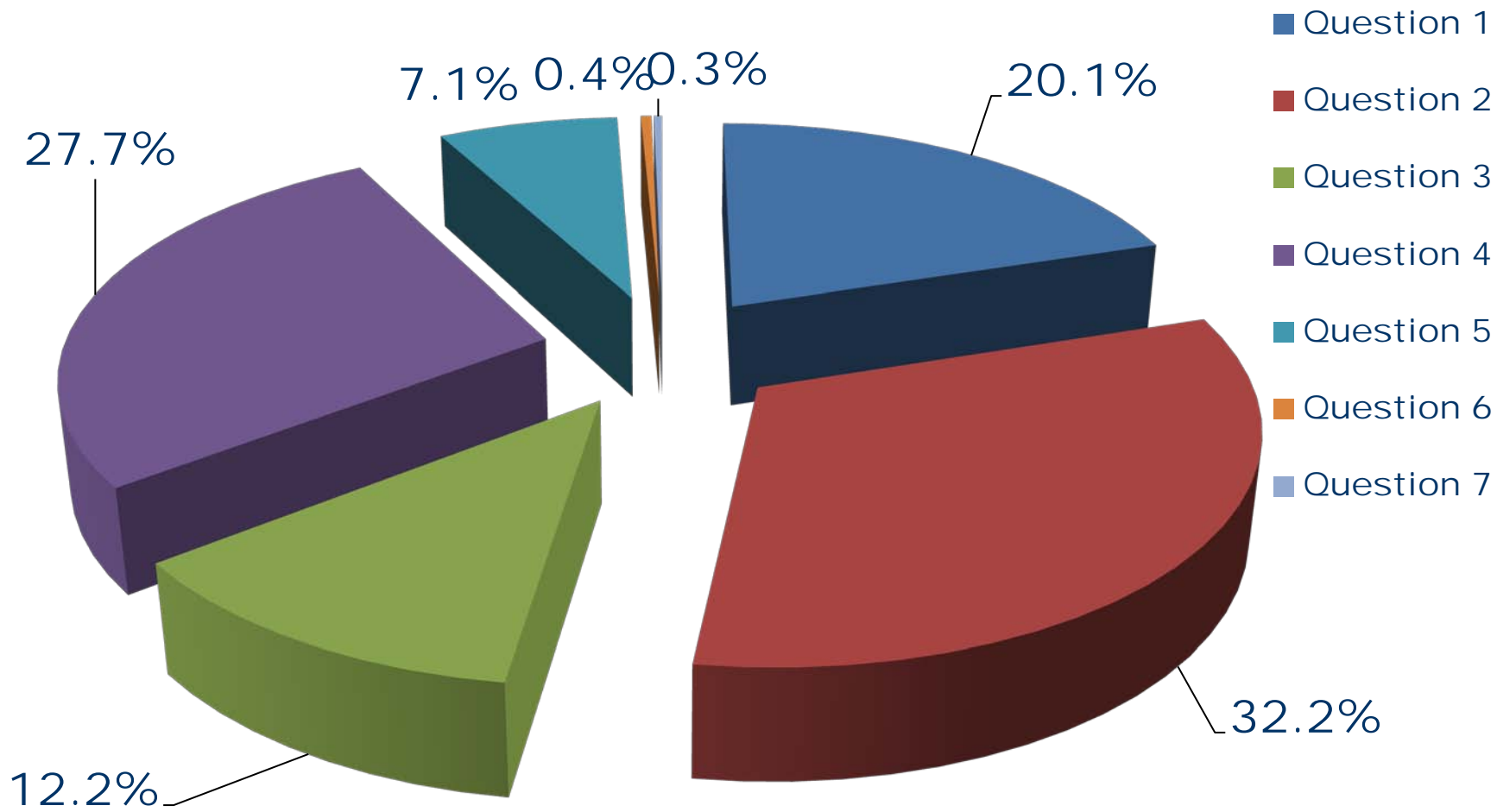




# How Does DoD ARP Fit: IACC Strategic Plan Objectives

Question 1	When should I be concerned?
Question 2	How can I understand what is happening?
Question 3	What caused this to happen and can it be prevented?
Question 4	Which treatments and interventions will help?
Question 5	Where can I turn for services?
Question 6	What does the future hold, particularly for adults?
Question 7	What other infrastructure and surveillance needs must be met?







# Advancing Access Through Technology



Wayne Fisher, Ph.D.  
University of Nebraska Medical Center  
*Technology-Enhanced Early Intensive  
Behavior Intervention Services for Children  
with ASD in Military Families*

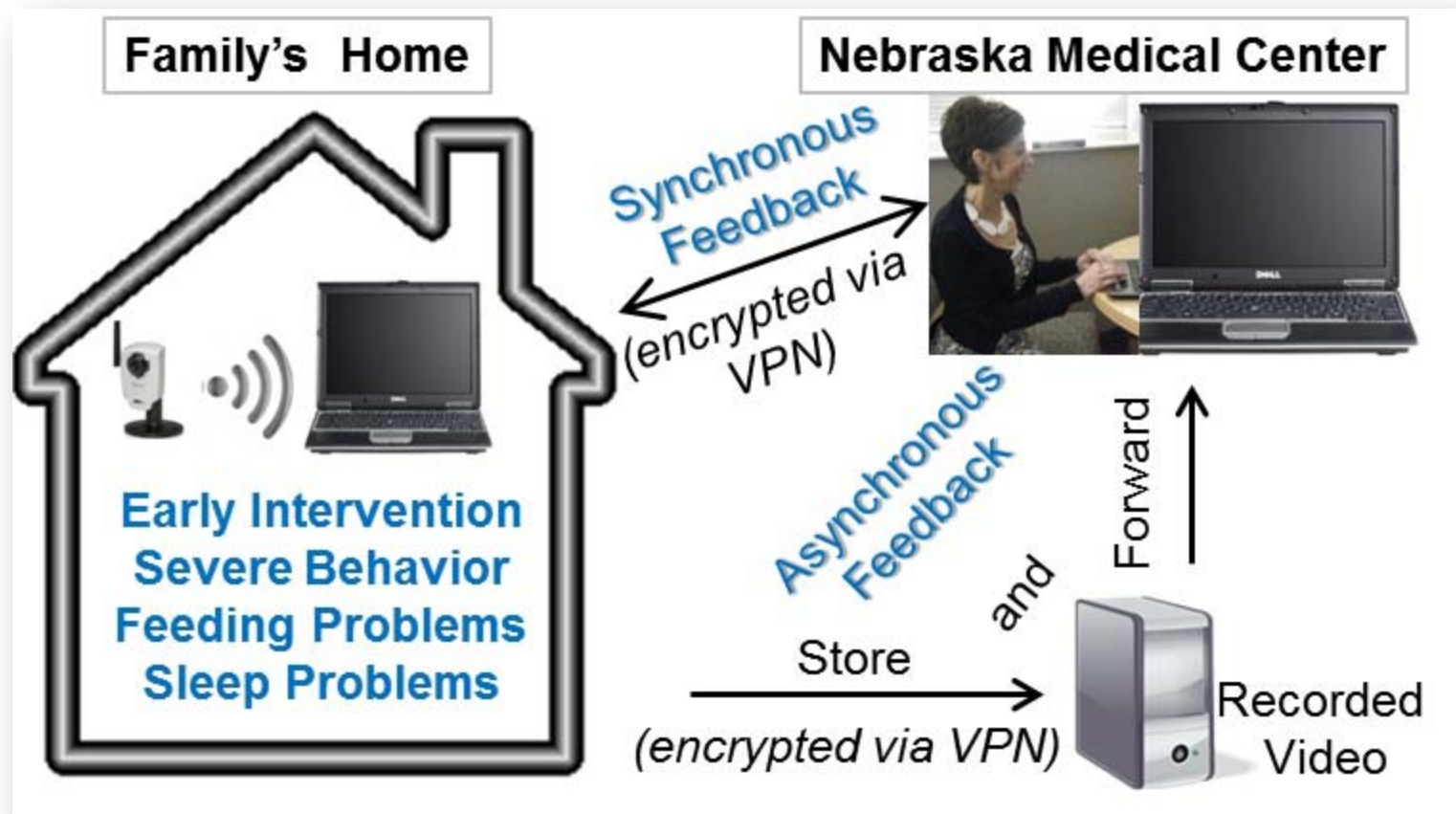


Brooke Ingersoll, Ph.D.  
Michigan State University  
*Development of Internet Based Parent  
Training Intervention for Children with ASD*



# *Technology-Enhanced Early Intensive Behavior Intervention Services for Children with ASD in Military Families*

Dr Wayne Fisher  
University of Nebraska Medical Center



# Advancing Independence

- Daniel Cox, Ph.D. and Ronald Reeve, Ph.D.  
University of Virginia
- Daniel Cox, Ph.D. and Timothy Brown, Ph.D.  
University of Virginia and University of Iowa  
*Evaluating and Enhancing Driving Skills of Individuals with ASD*



Virtual Reality Driver Simulator and Eye Tracking



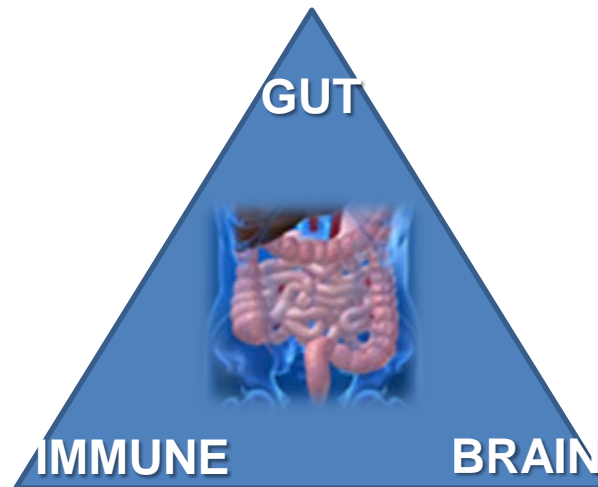
# Understanding the Immune System and ASD

➤ Armin Alaedini, Ph.D.

Columbia University

*Systematic Characterization of the Immune Response to Gluten and Casein in ASD*

*Proteomic Mapping of the Immune Response to Gluten in Children with ASD*



# Idea Development Awards – Nourishing the Future

**Improving Healthcare *Transition Planning and Health-Related Independence* for Youth with ASD and Their Families** - Nancy Cheak-Zamora, University of Missouri, Columbia

**Precursor to the Development of *Anxiety Disorders* in Young Children with Autism Spectrum Disorder** - Geraldine Dawson, Helen Egger, Duke University and Grace Baranek, University of North Carolina, Chapel Hill

**Proteomic Mapping of the *Immune Response* to Gluten in Children with Autism** - Armin Alaedini, Columbia University

**Brain Mechanisms of *Affective Language Comprehension* in Autism Spectrum Disorder** - Donald Bolder, University of Maryland, College Park

**Disruption of *Trophic Inhibitory Signaling* in Autism Spectrum Disorder** - Anis Contractor, Northwestern University

**Genetic and Diagnostic *Biomarker Development* in ASD Toddlers Using Resting State Functional MRI** - Peter Fox, University of Texas, Health Science Center at San Antonio, Eric Courchesne, University of California, San Diego, and David Glahn, Yale University

***Maternal Brain-Reactive Antibodies* and Autism Spectrum Disorder-** Betty Diamond, Feinstein Institute for Medical Research





# Pilot Awards – Exploration of Novel Ideas

## ***Autism and Obesity: Co-Occurring Conditions or Drug Side Effects?***

Zohreh Talebizadeh, Children's Mercy Hospitals and Clinics

## ***Mobile Device-Prompted Workplace Culture Analysis, Self-Efficacy, and Anxiety Reduction in the Transition to Independent Employment for Individuals with ASD***

David Hagner, University of New Hampshire

## ***Circadian Rhythms in Children with ASD and Their Infant Siblings***

Marc Taylor, Naval Medical Research Center

## ***Imaging Depression in Adults with ASD***

Kenneth Gadow, State University of New York, Stony Brook

## ***Implicit Learning Abilities Predict Treatment Response in ASD***

Catherine Lord, Cornell University, Weill Medical College

## ***Placental Identification and Immune Quantification of Acute and/or Chronic Inflammation in Children Diagnosed with ASD in University and Community Hospitals***

Carolyn Salafia, Research Foundation for Mental Hygiene, Inc., Staten Island



# Autism Research Program

## Vision

Improve the lives of individuals with autism spectrum disorder now



## Mission

Promote innovative research that advances the understanding of autism spectrum disorder and leads to improved outcomes





# http://cdmrp.army.mil

Congressionally Directed Medical Research Programs

**CDMRP**  
Department of Defense

HOME SITE MAP CONTACT US

Search CDMRP **SEARCH**

Finding and Funding the Best Research

RESEARCH PROGRAMS FUNDING OPPORTUNITIES CONSUMER INVOLVEMENT SEARCH AWARDS MEDIA CENTER ABOUT US

**CDMRP Research Funding for 2011/2012**

1 2 **3** 4 5 6

**Features**

**Research Programs**

**Funding Opportunities**

**Search Awards**

**Consumer Involvement**

**About Us**

**Duchenne Muscular Dystrophy Research Program**

**NEW Lung Cancer Research Program**

**Peer Reviewed Cancer Research Program**

**NEW Psychological Health and Traumatic Brain Injury Research Program**

CDMRP Research Funding for 2011 - Press Release



# Meeting of the IACC

---

## Morning Agenda - continued

**11:20 AM      National Database for Autism Research**

**Gregory K. Faber, Ph.D.**

Director

Office of Technology Development and  
Coordination

National Institute of Mental Health (NIMH)

**11:40            Teaching a Neurodiversity Course**

**John Elder Robison**

Self Advocate, Parent, Author

Neurodiversity Scholar in Residence

College of William & Mary

# Meeting of the IACC

---

## National Database for Autism Research

**Gregory K. Farber, Ph.D.**

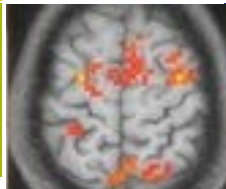
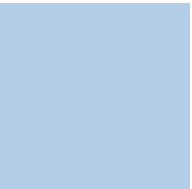
Director, Office of Technology Development and Coordination  
National Institute of Mental Health (NIMH)



# ***The National Database for Autism Research***

*April 8, 2014*

Greg Farber, Ph.D.  
Director  
Office of Technology Development and Coordination  
National Institute of Mental Health  
National Institutes of Health



# NDAR Overview

- Joint initiative supported by NIMH, NICHD, NINDS, and NIEHS
  - Federal data repository
  - Contains data from human subjects related to autism (and control subjects)
  - Data are available to the research community through a not too difficult application process
  - **Summary data are available to everyone with a browser**
- Begun in late 2006, and first data was received in 2008
- The data types include demographic data, clinical assessments, imaging data, and –omic data
- Currently has data available from nearly 70,000 subjects
- ~400TB of imaging and –omic data is securely stored in the cloud

# NDAR Implementation

- NDAR has deep federation with the following data repositories. This federation allows NDAR to query data in those repositories and to return data to the user from multiple repositories simultaneously.
  - Autism Tissue Program
  - Autism Genetic Resource Exchange
  - Interactive Autism Network
  - Simons Foundation Autism Research Initiative
- NDAR has two key features to allow data standardization and aggregation: data dictionaries and the Global Unique Identifier (GUID)
- Generally, NIH funded investigators are expected to share their data via NDAR. Investigators with funding from other sources are welcome to deposit their data.
- Over 150 studies have registered data.

# Data Dictionary

- The NDAR data dictionary is one of the key building blocks for this repository. It provides a flexible and extensible framework for data definition by the research community.
- 500+ instruments, freely available to anyone
  - 50,000+ unique data elements and growing
  - A research community platform for defining the complex language characterizing autism research
    - Clinical
    - Genomics/Proteomics
    - Imaging Modalities
- Accommodates any data type and data structure
- Extended and enhanced by the ASD research community
- **Curated by NDAR**
- **Allows investigators to quickly perform quality control tests of their data without submitting data anywhere.**





## Data Dictionary

## Resolve Subject Identifiers

## Harmonization Standards

Type:

All

Source:

All

Category:

All

TITLE	SHORT NAME	Category:	SOURCE	CATEGORY	SUBMISSION	CHANGE HISTORY
<a href="#">ACE Family Medical History</a> <small>new</small>	ace_fammedhist01	All	ACE	Med History	Allowed	
<a href="#">ACE Subject Medical History</a> <small>new</small>	ace_subjmedhist01	Acoustics	Common Measures V2, NDAR	Med History	Allowed	<a href="#">show changes</a>
<a href="#">ACE Subject Physical Exam</a> <small>new</small>	ace_physexam01	Behavior	ACE	Phys Exam	Allowed	
<a href="#">AGRE ADOS Module 1 2001</a>	agre_ados1_200102	Cognitive	Common Measures V2, NDAR	Diagnostic	Not	
<a href="#">AGRE ADOS Module 2 2001</a>	agre_ados2_200102	DTI	AGRE	Diagnostic	Not	
<a href="#">AGRE ADOS Module 3 2001</a>	agre_ados3_200102	Demographics	AGRE	Diagnostic	Not	
<a href="#">AGRE ADOS Module 4 2001</a>	agre_ados4_200102	Diagnostic	AGRE	Diagnostic	Not	
<a href="#">AGRE ADOS-G Module 1 (2000 or earlier)</a>	agre_ados1_pre200002	EEG	AGRE	Diagnostic	Not	
<a href="#">AGRE ADOS-G Module 2</a>	agre_ados2_pre200002	ERP	AGRE	Diagnostic	Not	
		Exposure	AGRE	Diagnostic	Not	
		Gen Test	AGRE	Diagnostic	Not	
		IQ	AGRE	Diagnostic	Not	
		MEG	AGRE	Diagnostic	Not	
		MRI	AGRE	Diagnostic	Not	
		Med History	AGRE	Diagnostic	Not	
		Phys Characteristics	AGRE	Diagnostic	Not	
		Phys Exam	AGRE	Diagnostic	Not	
		Questionnaire	AGRE	Diagnostic	Not	
		Resolve Identifiers	AGRE	Diagnostic	Not	
		Social Responsiveness	AGRE	Diagnostic	Not	
		Clinical Assessments	AGRE	Diagnostic	Not	

## CPEA STAART ADOS G Module 4

Short Name: cs\_adog\_4

Version: 02

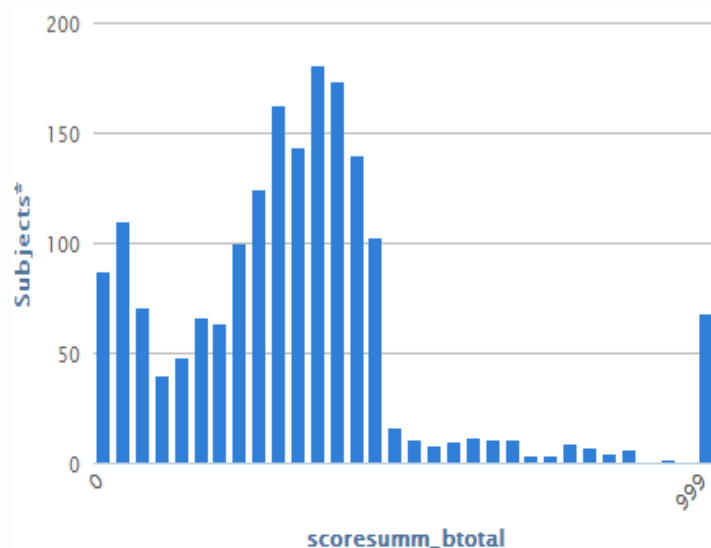
### ADOS G Module 4 as defined by the CPEA STAART project

[Download Definitions](#)

ElementName	DataType	Size	Required	ElementDescription	ValueRange	Notes	Aliases
subjectkey	GUID		Required	The NDAR Global Unique Identifier (GUID) for subjects which identifies a subject in NDAR	NDAR*		
interview_date	Date		Required	Date on which the interview/genetic test/sampling/imaging was completed		Required field	ADOS_DATE_STD
cycle	Integer		Recommended	Timepoint information			
patid	String	20	Recommended	src_Subject_id		A Participant ID provided by DM-STAT must be present to process form	
network	String	20	Recommended	Network		CPEA or STAART Network	
site	String	20	Recommended	Site		Study Site	
study	String	100	Recommended	Study		CPEA or STAART Study	
ados_alg_cmsit	Integer		Recommended	Communication Social Interaction Total	0 :: 24		
ados_alg_commt	Integer		Recommended	Communication Total	0 :: 10		
ados_alg_imgcr	Integer		Recommended	Imagination Creativity	0 :: 2		
ados_alg_sbrit	Integer		Recommended	Stereotyped Behaviors and Restricted Interests Total	0 :: 6		
ados_alg_sbrits	Integer		Recommended	ADOS: Stereotyped Behaviors-Restricted Interests Severity Score			
ados_alg_sclit	Integer		Recommended	Social Interaction Total	0 :: 14		
ados_alg_sclits	Integer		Recommended	ADOS: Social Severity Score			
ados_date	Integer		Recommended	ADOS Date			
ados_dia_class	String	50	Recommended	ADOS Classification			
ados_dia_diag	String	75	Recommended	Overall Diagnosis			
ados_dx	String	15	Recommended	ADOS Diagnosis			
ados_lac_afinf	Integer		Recommended	Asks for Information		Nullled value range of: 0;1;2;3 to accept outlier data	

csa6

## Distribution for Data Structure: ados1\_200102 and Element: scoresumm\_btotal

 to 

Add Range

\* 112 subjects have no value provided for scoresumm\_btotal

## Description

Social Interaction Total

## Value Range

No Restriction

## Notes

None Provided

## Filters

No filters currently applied. Click bar on chart to add filter.

Return

coresumm\_a\_a7  
coresumm\_a\_a8  
coresumm\_atotal  
coresumm\_a\_b1  
coresumm\_a\_b3  
coresumm\_a\_b5  
coresumm\_a\_b9  
coresumm\_a\_b10  
coresumm\_a\_b11  
coresumm\_a\_b12  
coresumm\_btotal  
coresumm\_abtotal  
coresumm\_a\_c1  
coresumm\_a\_c2  
coresumm\_ctotal  
coresumm\_a\_d1  
coresumm\_a\_d2  
coresumm\_a\_d4

1\_scoresumm\_a7  
ECT csa7  
1\_scoresumm\_a8  
IRE csa8  
1\_scoresumm\_ato  
ATION\_TOTAL CSS  
n ados\_mod1\_com  
1\_scoresumm\_b1  
sb1  
1\_scoresumm\_b3  
PRESS\_DIRECT sb3  
1\_scoresumm\_b5  
OY\_INTERACT sb5  
1\_scoresumm\_b9  
e sb9  
1\_scoresumm\_b10  
OINT\_ATTN sb10  
1\_scoresumm\_b11  
JOINT\_ATTN RJA\_r  
1\_scoresumm\_b12  
de SOCIAL\_OVRTU  
1\_scoresumm\_bto  
CIAL\_INTERACT\_TO  
\_soc\_int\_total ad  
1\_scoresumm\_abt  
SOC\_INTERACT\_1  
c\_ttl ados\_mod1\_c  
omm sabtotal  
1\_scoresumm\_c1  
PLAY\_TOY PLAY\_re  
1\_scoresumm\_c2  
le sc2  
1\_scoresumm\_cto  
AY\_TOTAL ados\_m  
sctotal  
1\_scoresumm\_d1  
SENSE\_INTERST sd  
1\_scoresumm\_d2  
1\_scoresumm\_d4

# Global Unique Identifier – the Other Building Block

- The NDAR GUID software allows any researcher to generate a unique identifier using some information from a birth certificate.
- If the same information is entered in different laboratories, the same GUID will be generated.
- This strategy allows NDAR to aggregate data on the same subject collected in multiple laboratories without holding any of the personally identifiable information about that subject.
- The GUID is now being used in other research communities and can be made available to you. We have created a video to help with informed consent issues.

<http://www.youtube.com/watch?v=Tb6euCVoous>



## Quick Navigation

### Query

- [General Query](#)
- [Data from Labs](#)
- [Data from Papers](#)
- [By Measure/Element](#)
- [By Concept \(beta\)](#)
- [omicSearch \(beta\)](#)

### Share

- [Harmonization Standards](#)
- [Prepare and Submit](#)

### Compute

### Resources

- [GUID Tool](#)
- [Validation Tool](#)
- [Download Manager](#)
- [Data Dictionary](#)
- [Contact Us](#)
- [Request Account](#)

## NDAR News

Recent news is available from the "About NDAR" page.

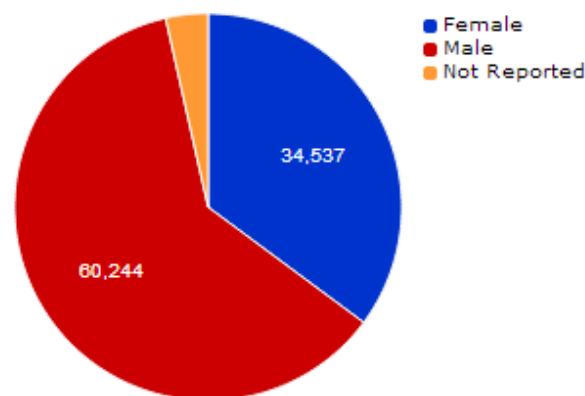
## Learn About NDAR

The National Database for Autism Research (NDAR) is an NIH-funded research data repository that aims to accelerate progress in autism spectrum disorders (ASD) research through data sharing, data harmonization, and the reporting of research results. NDAR also serves as a scientific community platform and portal to multiple other research repositories, allowing for aggregation and secondary analysis of data.

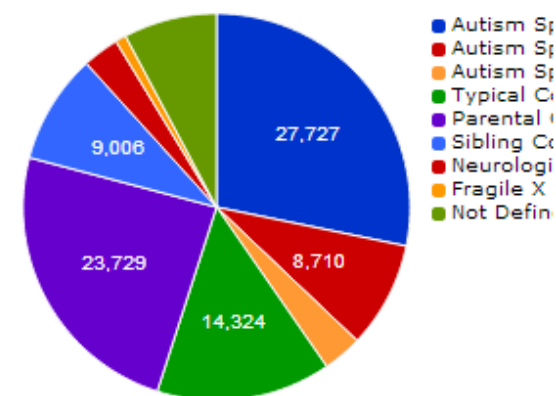
## Data Distribution

98,239 subjects by age, 69,719 individuals

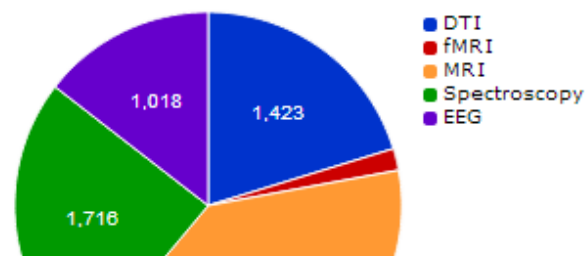
### Gender<sup>1</sup>



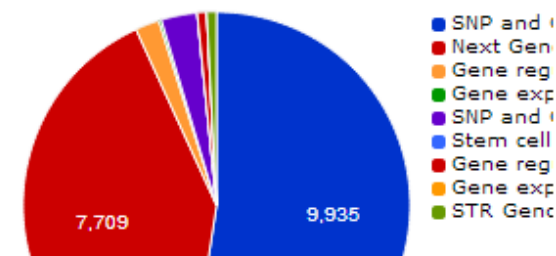
### Phenotypic<sup>1</sup>



### Neuroimaging



### Genomic



# An Example of Data Associated with a Particular Laboratory

National Database for Autism Research - Data - Data from Labs - Mozilla Firefox

File Edit View History Bookmarks Tools Help

National Database for Autism Research - ...

www.ndar.nih.gov/data\_from\_labs.html

Google

**Collection Title:** *Biological and Information Processing Mechanisms Underlying Autism*

**Investigators:** Nancy Minshew, M.D. Mark Strauss, Ph.D. Kevin Pelphrey, Ph.D. Marcel Just, Ph.D. Thomas Mitchell, Ph.D. Diane Williams, Ph.D. (Owner: Minshew, Nancy)

**Collection Description:** This center focuses on elucidating fundamental information processing and neurobiological mechanisms causing autism with studies of infant siblings, first-diagnosed toddlers, and groups of children, adolescents, and adults with and without autism. Project I: Development of Categorization & Facial...

**Download Data**

**Grant Information:**

Project Number	Project Title	Start Date	End Date	Organization
P50HD55748	Biological and Information Processing Mechanisms Underlying Autism	08/06/2007	07/31/2012	UNIVERSITY OF PITTSBURGH AT PITTSBURGH

**Publications** (Showing 3 of 39) [Show All](#)

**Bishop-Fitzpatrick, Lauren; Minshew, Nancy J; Eack, Shaun M** "Journal of autism and developmental disorders" *A Systematic Review of Psychosocial Interventions for Adults with Autism Spectrum Disorders.*

**Dundas, Eva M; Best, Catherine A; Minshew, Nancy J; Strauss, Mark S** "Journal of autism and developmental disorders" *A lack of left visual field bias when individuals with autism process faces.*

**Mazefsky, Carla A; Oswald, Donald P; Day, Taylor N; Eack, Shaun M; Minshew, Nancy J; Lainhart, Janet E** "Journal of clinical child and adolescent psychology : the official journal for the Society of Clinical Child and Adolescent Psychology, American Psychological Association, Division 53" *ASD, a psychiatric disorder, or both? Psychiatric diagnoses in adolescents with high-functioning ASD.*

**Data Structures:**

Title	Type	Number of Subjects
Autism Diagnostic Interview, Revised (ADI-R)	Clinical Assessments	212
Autism Diagnostic Observation Schedule - Module 1	Clinical Assessments	97
Autism Diagnostic Observation Schedule - Module 2	Clinical Assessments	67
Autism Diagnostic Observation Schedule - Module 3	Clinical Assessments	105
Autism Diagnostic Observation Schedule - Module 4	Clinical Assessments	200
Benton Facial Recognition Test	Clinical Assessments	341
CELF-4 Clinical Eval of Lang Fundamentals, 4th ed	Clinical Assessments	33
CHARGE Family Characteristics Questionnaire	Clinical Assessments	399
CHARGE Medical History	Clinical Assessments	312
CHARGE Physical Exam	Clinical Assessments	299

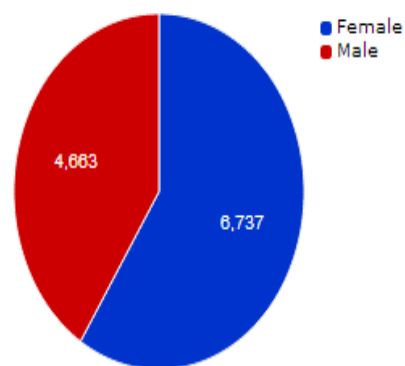
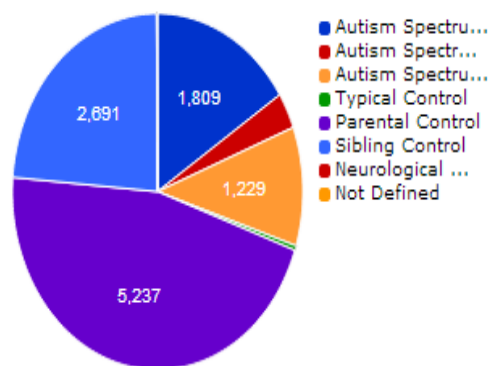
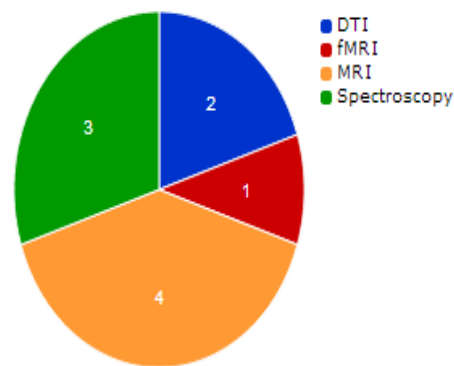
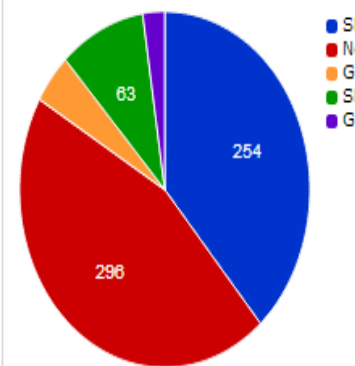
**Genomics** **Neuroimaging** **Phenotype**

85 91 790 466



**Showing all of the data  
in IAN**

Use "Select Data" below to query the data available in NDAR. Then, select download to create a package and download your results. Use the Data tab above to search in other ways. For more information on search see our [Methods](#).

**Data Distribution by Gender<sup>1</sup>****Phenotypic Data Distribution<sup>1</sup>****Neuroimaging Data Distribution****Genomic Data Distribution**<sup>1</sup> Numbers reported are subjects by age[Select Data:](#) [All](#) [Basic](#) [Phenotype](#) [Neuroimaging](#) [omicSEARCH:](#) [Experiment](#) [Results](#)[Show Results](#)[Reset All](#)[Download Data](#)

Showing results 1 - 50 of 11,400

Results per Page: [50](#)

Showing page 1 of 228

Jump to Page: [1](#)

DATA SOURCES	SUBJECT ID	INTERVIEW AGE	GENDER	NDAR CATEGORY	CLINICAL DIAGNOSIS	ADI SCORE	ADOS CLINICAL DIAGNOSIS
Interactive Autism Network	8	132	MALE	SIBLING CONTROL	SIBLING CONTROL		
Interactive Autism Network	9	135	MALE	SIBLING CONTROL	SIBLING CONTROL		
Interactive Autism Network	12	384	FEMALE	PARENTAL CONTROL	PARENTAL CONTROL		
Interactive Autism Network NDAR	14	108	MALE	AUTISM SPECTRUM AFFECTED	AUTISM SPECTRUM AFFECTED		
Interactive Autism Network	15	108	MALE	AUTISM SPECTRUM AFFECTED	AUTISM SPECTRUM AFFECTED		

In Beta

Below are defined ontological concepts that can be used to query all NDAR and federated data. Select a concept and apply the filter to see the number of subjects available. Those that have access may then download. NDAR adopted the published ASD phenotype ontology defined in [Modeling the Autism Spectrum Disorder Phenotype](#) (McCrack et al) as an initial implementation of ontological concepts. For changes or additions to the current model, contact us at [ndarhelp@mail.nih.gov](mailto:ndarhelp@mail.nih.gov).

Available Concepts (1 selected)

Clear Selections Collapse All

General Parameters

Age in Months From: 0 To: 1200

Gender Both ▼

**Personal Traits**

- ☒ Cognitive Ability
- ☒ Executive Function
- ☒ Language Ability
- ☒ Motor Skills
- ☒ **Stereotyped, Restricted, and Repetitive Behavior**
  - ☒ Involuntary Behaviors
  - ☒ **Restricted and Repetitive Behavior**
    - ☒ **Adherence to Rituals and Routines**
      - ☒ Insistence on Order
      - ☒ Insistence on Routine
      - ☒ **Repetitive Actions**
        - ☒ Excessive Repetitive Actions ⓘ
        - ☐ No Repetitive Actions ⓘ
    - ☒ Compulsive Behavior

Apply Filters

Personal Traits &gt; Stereotyped, Restricted, and Repetitive Behavior &gt; Restrict...

**Concept:** Personal Traits > Stereotyped, Restricted, and Repetitive Behavior > Restricted and Repetitive Behavior > Adherence to Rituals and Routines > Repetitive Actions > Excessive Repetitive Actions

**Rules:** ⓘ cddl66 in (1;2)  
ⓘ rbsr\_q18 between (1::3)  
ⓘ rbsr\_q21 between (1::3)  
ⓘ rbsr\_q22 between (1::3)  
ⓘ scl65 in (moderately; quite a bit; extremely;)  
ⓘ rbsr\_q5 between (1::3)

OK

Results in 750 subjects  
being discovered

# Imaging and Genomic Data

- In the past 2 years, NDAR has accumulated significant imaging and genomics data.
- Both of these data types are harder to query and make easily useful than the clinical and demographic data in NDAR.
- We are very interested in working with anyone who is interested to collaborate on ways to query the data or on ways to create data processing pipelines that can work on the data we have in the cloud.
- Current collaborators: David Kennedy and Jack Van Horn for imaging, Evan Eichler in genomics.

# How is NDAR being used?

- With biological databases, it is not true that if you build it they will come.
- More than 270 users have been granted access to NDAR. Data access is separate from those who are depositing data.
- David Hessel and collaborators used NDAR to collect and analyze their data in a private space before publication (“Psychometric study of the aberrant behavior checklist in Fragile X syndrome and implications for targeted treatment”, J. Autism Dev. Disord. (2012), 42:1377-1392).
- David M. Richman and colleagues have published a study, “Predictors of self-injurious behavior exhibited by individuals with autism spectrum disorder” where all of the data in the paper came from NDAR (J. Intellect. Disabil. Res. (2013), 57:429-439).
- Vinod Menon and colleagues have published a paper, “Brain hyperconnectivity in children with autism and its links to social deficits” (Cell Rep. (2013), 5(3), 738-747. where some of the data is from NDAR and some is newly measures.
- Many are using data from NDAR as part of NIH grant applications.



# Summary

NDAR, is a useful data archive that makes autism data:

- A) Discoverable – federation, useful queries, XML web services
- B) Useful to Others – data access, data QC, data analysis pipelines
- C) Citable – data from labs, data from papers
- D) Linked to the Literature – data link in PubMed



# Meeting of the IACC

---

## Teaching a Neurodiversity Course

**John Elder Robison**

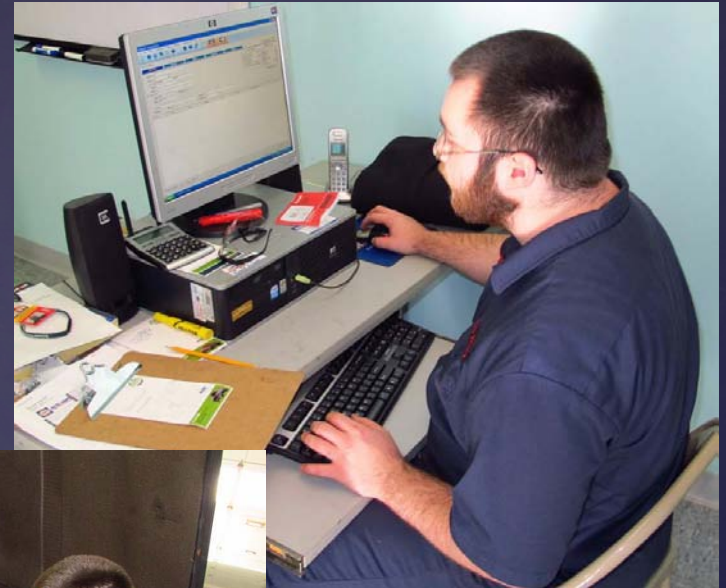
Self Advocate, Parent, Author  
Neurodiversity Scholar in Residence  
College of William & Mary



# Teaching a Neurodiversity Course at College of William & Mary



# TCS Automotive Program





# Teaching at College of William & Mary

- What makes a nation, a region or a city a compelling place to live, work and do business?
- What makes a business want to relocate, stay, expand or grow in an area?
- What is the right balance of initiatives to achieve citizen satisfaction and sustained competitive advantage in the marketplace?

**TED<sup>x</sup>** College of William & Mary



# **Meeting of the IACC**

---

## **Lunch Break**

# Meeting of the IACC

---

## Afternoon Agenda

**1:00                      Public Comments and Discussion**

**2:00                      Services Research for ASD across the  
                                 Lifespan (ServASD)**

**Denise Juliano-Bult, Ph.D.**

Program Chief

National Institute of Mental Health (NIMH)

**2:15                      Autism Policy Update**

**Stuart Spielman, Esq.**

Senior Policy Advisor and Counsel

Autism Speaks

# **Meeting of the IACC**

---

## **Public Comments and Discussion**



# Meeting of the IACC

---

## Services Research for Autism Spectrum Disorder across the Lifespan

**Denise Juliano-Bult, Ph.D.**  
Program Chief  
National Institute of Mental Health



# Services Research for Autism Spectrum Disorder Across the Lifespan

Denise Juliano-Bult, M.S.W.

*Division of Services and  
Intervention Research, NIMH*

April 8, 2014



National Institute  
of Mental Health

# RFAs in ASD Services Research

- Research on Early Identification and Linkage to Services for ASD
- Pilot Studies on Services for Transition-Age Youth
- Pilot Studies on Services for Adults with ASD

 Intent to commit \$10,000,000 in FY 2014

# Purpose of Announcements

“... research that develops and tests the effectiveness of service system interventions to improve functional and health outcomes for people with autism spectrum disorder at three key life stages: early childhood, transition from youth to adulthood, and adulthood.”

# NIMH Response to IACC Strategic Plan Update

Question 1: When Should I Be Concerned?

Question 5: Where Can I Turn For Services?

Question 6: What Does the Future Hold, Particularly for Adults?



# Early Identification & Linkage to Services Announcement

- Develop an intervention that coordinates ASD screening, evaluation and linkage to treatment and services within the first two years of life
- Test feasibility and effectiveness of the intervention in engaging young children in care
- Demonstrate the intervention's implementability and generalizability to settings across the US
- Reduce disparities in outcomes for underserved populations



# Services for Transition-Age Youth Announcement

- Develop service strategies to assist youth and families in transition to adult functioning and services without lapses in services and supports
- Enhance functioning in: post-secondary education or training; employment; social, familial, and other settings, etc.
- Maintain or improve health, safety, and quality of life and reduce or maintain reduction in ASD-related symptoms
- Reduce disparities in outcomes for underserved populations

# Services for Adults Announcement

- Develop service strategies that optimize the independence and functioning of adults with ASD
- Targeted areas include: employment or training; community housing and safety; social relationships; physical and mental health, etc.
- Improve behavioral, functional and health outcomes
- Reduce disparities in outcomes for underserved populations

# Time Line

- Issued: May 30, 2013
- Receipt: November 1, 2013 (extended due to furlough)
- Review: March 14, 2014

# Results to Date: 36 Applications Received

- Children = 12
- Transition-Age = 15
- Adults = 9

# Next Steps for Funding Decisions

- Review & Response to Summary Statements - Current
- Discussions Internal to NIMH - Current
- Discussion with NIMH Advisory Council – May 2014 ★
- Earliest Start Date – July 2014

# Meeting of the IACC

---

## Autism Policy Update

**Stuart Spielman, Esq.**  
Senior Policy Advisor and Counsel  
Autism Speaks





# ABLE Act of 2013

Stuart Spielman  
Senior Policy Advisor and Counsel  
Autism Speaks

- The ABLA Act of 2013 (H.R. 647/S.313) would amend section 529 of the Internal Revenue Code to encourage savings for the needs of an individual with a disability, whether or not those needs include savings for higher education. Current 529 plans can fall short for the many individuals with autism or other severe disabilities who cannot or choose not to pursue post-secondary education.
- ABLA accounts would help people with disabilities enjoy greater financial security by supplementing benefits provided through private insurance, employment, the supplemental security income (SSI) program, the Medicaid program, or other sources.



- **ABLE accounts could be used for a variety of purposes, including the following:**
  - **Education**, including tuition for preschool through post-secondary study, tutors, and special education services;
  - **Housing**, including expenses for acquiring, modifying, and maintaining a primary residence;
  - **Transportation**, including expenses for using mass transit, purchasing and modifying vehicles, and moving;
  - **Employment support**, including expenses for obtaining and maintaining a job, such as job-related training, assistive technology, and personal assistance supports
  - **Health and wellness**, including premiums for health insurance, mental health, medical, vision, and dental expenses, habilitation and rehabilitation services, durable medical equipment, therapy, respite care, long term services and supports, nutritional management, communication services and devices, adaptive equipment, assistive technology, and personal assistance; and
  - **Miscellaneous expenses** such as funeral and burial expenses.



- ABLE Accounts are not intended to replace special needs trusts (individual or pooled) as an option for financial planning.
- ABLE accounts would be available for individuals who receive SSI or disability benefits. They would also be available under stringent conditions for individuals who are not receiving these benefits but who have a medically determined physical or mental impairment that results in marked and severe functional limitations.
- A key feature of ABLE accounts is their treatment under means-tested federal programs such as SSI and Medicaid. If the assets in an ABLE account reached \$100,000, any monthly SSI benefits would be suspended but not terminated. Suspension of SSI benefits would have no impact on an individual's Medicaid eligibility.



- The ABLE Act is supported by a bipartisan, bicameral group of champions, including Senator Robert Casey, Jr. (D-PA) and Senator Richard Burr (R-NC); and Representative Andre Crenshaw (R-FL), Representative Chris Van Hollen (D-MD), Representative Cathy McMorris Rodgers (R-WA), and Representative Pete Sessions (R-TX). **Seventy senators and 354 representatives are cosponsoring ABLE.**



# Meeting of the IACC

---

## Afternoon Agenda – continued

**2:30                      Committee Business**

**3:30                      Break**

**3:45                      Committee Business - Continued**

**4:00                      Round Robin**

**5:00                      Adjournment**

**Next IACC Full Committee Meeting:**

**July 9, 2014** – *6001 Executive Boulevard, Neuroscience Center,  
Conference Rooms C and D, Rockville, MD 20852*



# Meeting of the IACC

---

## Committee Business

**Thomas Insel, M.D.**  
Director, NIMH and Chair, IACC

**Susan Daniels, Ph.D.**  
Director, OARC, NIMH and Executive Secretary, IACC

# Meeting of the IACC

---

## OARC Update

**Susan A. Daniels, Ph.D.**

Director, Office of Autism Research Coordination, NIMH  
and Executive Secretary, IACC

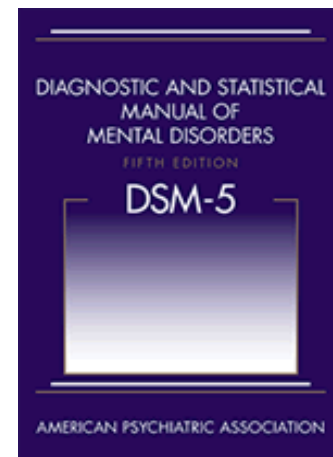
# Combating Autism Act Report to Congress (FY 2010- FY 2012)



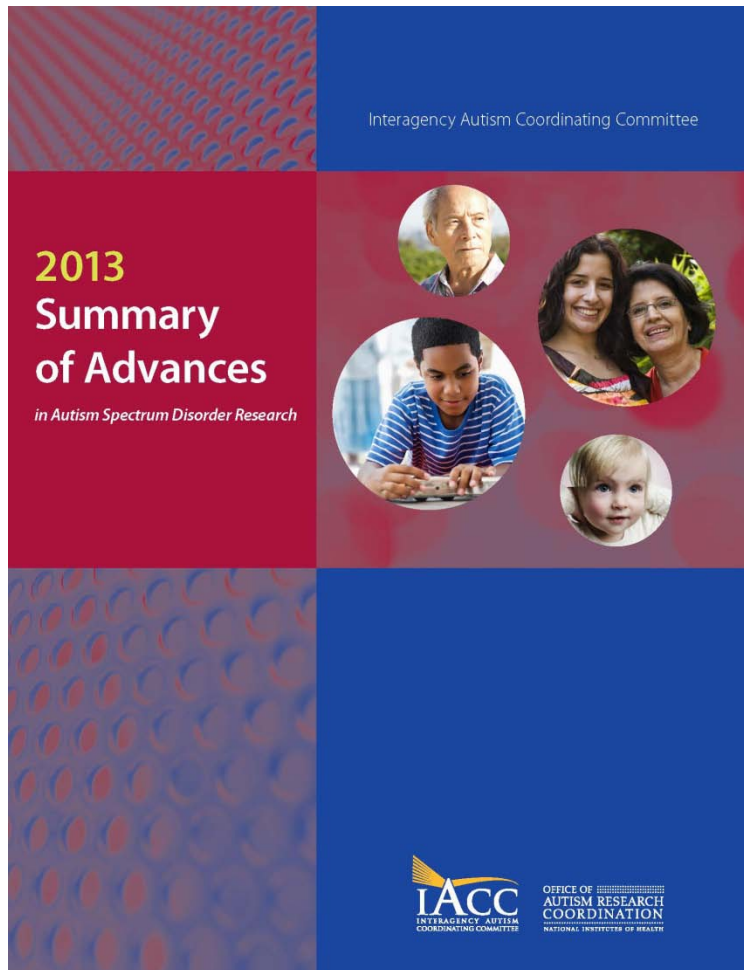
- 100+ page report encompasses information on autism-related activities and programs (research and services) of agencies and offices within HHS, Department of Education, Environmental Protection Agency, Department of Defense, and National Science Foundation
- Released in February, 2014 and submitted to Congress per CARA
- Available online at [www.iacc.hhs.gov](http://www.iacc.hhs.gov)

# IACC Statement on DSM-5

- IACC issued a statement regarding the implications of changes in the ASD diagnostic criteria
  - Addresses implications for:
    - Research
    - Practice and Policy
  - Key points:
    - Committee recommended research to further assess the reliability and validity of the *DSM-5* ASD criteria, and to understand the potential impact of these new criteria on diagnosis, prevalence estimates, and access to services.
- "Services should be based on need rather than diagnosis; it would not be appropriate for a child to be denied ASD-specific services because he or she does not meet full DSM-5 criteria if a qualified clinician or educator determines that the child could benefit from those services."**
- [www.iacc.hhs.gov/news/press\\_releases/2014/pr\\_2014\\_dsm5.shtml](http://www.iacc.hhs.gov/news/press_releases/2014/pr_2014_dsm5.shtml)



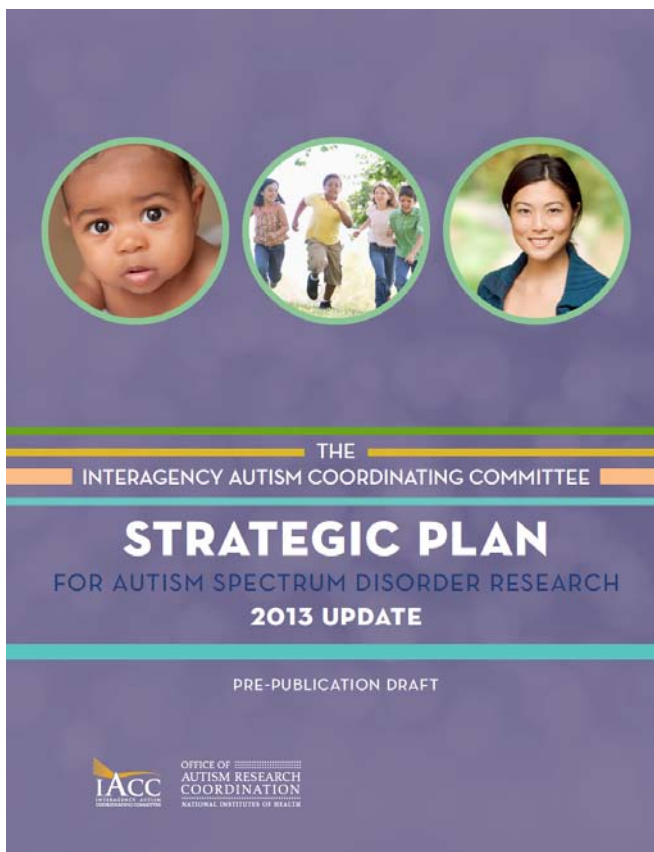
# Preview: 2013 IACC Summary of Advances



- Annual publication – required by CAA
- Lay-friendly summaries of the 20 most significant advances in ASD biomedical and services research selected by the IACC
- Covers:
  - Prevalence
  - Diagnosis
  - Biology
  - Risk factors
  - Interventions
  - Lifespan issues

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

# Preview: 2013 IACC Strategic Plan Update



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

**Provides five-year update on progress toward IACC Strategic Plan goals**

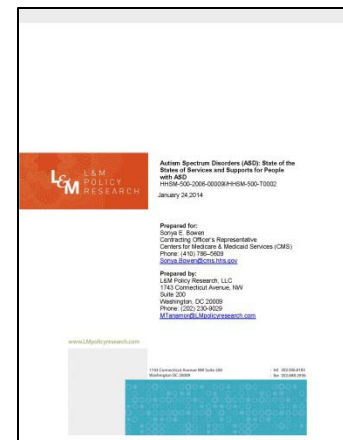
**Includes:**

- **Portfolio analysis data for FY 2008-2012**
- **Funding allocated to each Objective of the IACC Strategic Plan**
- **Assessment of which objectives met, partially met, or did not meet recommended funding levels**
- **Assessment of:**
  - **Key research findings and progress**
  - **Remaining gaps in knowledge**
  - **Emerging needs and opportunities**
  - **Progress toward aspirational goals**



# State of the States of Services and Supports for People with ASD

- Released by CMS, January 2014.
- Contains data on existing federal and state-level services programs/policies for people with ASD in all 50 states and D.C.
- Responded to Objective 7B of the *Strategic Plan* which reflected the need among policymakers and stakeholders for accurate and comprehensive information:  
“Conduct an annual "State of the States" assessment of existing State programs and supports for people and families living with ASD by 2011.”
- Answered the following questions:
  - What are states and/or local government doing to provide services for people with ASD?
  - What are the types and supports that a person with ASD can access?
  - How are these supports and services funded?
- <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Downloads/ASD-State-of-the-States-Report.pdf>

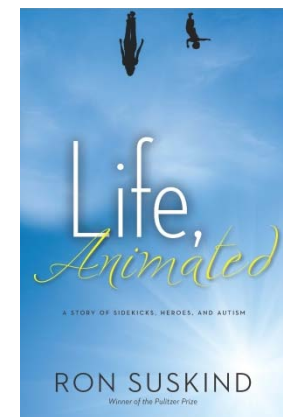


NIMH SPECIAL LECTURE FOR AUTISM  
AWARENESS MONTH • APRIL 24, 2014 • 4pm

**AUTISM'S POWERFUL AFFINITIES:  
PRISON OR PATHWAY?** -RON SUSKIND



- Speaker: Ron Suskind, Pulitzer Prize-winning journalist and *New York Times* bestselling author.
- Location: Lipsett Ampitheater, NIH Clinical Center (Building 10), NIH, Bethesda
- Book signing: 3-3.30pm (before the lecture) at the FAES bookstore (Building 10)
- Free and open to the general public. No prior registration is required.
- Free live webcast ([www.videocast.nih.gov](http://www.videocast.nih.gov))



# Autism Awareness Month 2014

---

## Events

- **NICHD Conference on Military Connected Children with Special Health Care Needs and their Families. April 14-15, NIH Campus, Bethesda, MD**
- **NIMH Twitter Chat: “When should I be concerned?” with NIMH researchers Dr. Sue Swedo and Dr. Audrey Thurm. April 29, 2-3pm ET**
- **NIEHS Virtual Forum: Autism and the Environment. April 22, 2-3pm ET, Webcast live**

# **Autism Awareness Month 2014**

---

## **Events continued**

- **CDC Autism Awareness Event 2014: Panel, featuring Alexis Wineman, discussing challenges facing teens and adults with ASD. April 17, 5:30-7:30pm ET, Tom Harkin Global Communications Center, Atlanta, GA**
- **CDC Grand Rounds - Autism Spectrum Disorder: From Numbers to Know-How. April 22, 1-2pm ET**
- **HRSA/AUCD Virtual Forum on ASD and Transition. April 30, 3-4.30pm ET**
- **HRSA/AUCD Virtual Forum on Reducing Disparities for People with ASD. May (TBD)**

# GAO Letter Update

---

- Group of IACC Public Members sent letter to GAO on March 6, 2014
- Response letter from GAO received April 3, 2014
- Letters can be viewed at:  
<http://iacc.hhs.gov/reports/index.shtml>

# Meeting of the IACC

---

## Break



# Meeting of the IACC

---

## Committee Business - continued

**Thomas Insel, M.D.**  
Director, NIMH and Chair, IACC

**Susan Daniels, Ph.D.**  
Director, OARC, NIMH and Executive Secretary, IACC

# Co-occurring Conditions Planning Group

---

- **Goal: To develop and complete a project to address conditions that co-occur with ASD**
  
- **IACC Members:**
  - Thomas Insel
  - Lyn Redwood
  - Anshu Batra
  - Sally Burton-Hoyle
  - Judith Cooper (for James Battey)
  - Jan Crandy
  - Alice Kau (for Alan Guttmacher)
  - Donna Kimbark
  - Walter Koroshetz
  - Alison Singer

# Co-occurring Conditions Planning Group

---

## Task for today

- **Determine the Group's Charge**
- **Decide on Project Types/Product:**
  - Statement?
  - Letter?
  - Workshop?
  - List of recommendations?
  - Other?

# Meeting of the IACC

---

## Round Robin

# **Next IACC Meeting**

---

## **July 8, 2014**

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

# **Meeting of the IACC**

---

## **Adjournment**