Meeting of the Interagency Autism Coordinating Committee

April 8, 2014

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

Conference Call Access:
Phone: (888) 950-8042
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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

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Science Update

Thomas R. Insel, M.D.
Director, National Institute of Mental Health and Chair, IACC
IACC Full Committee Meeting – April 8, 2014

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Q1. When should I be concerned?

February 19, 2014

Longitudinal patterns of repetitive behavior in toddlers with autism

March 13, 2014

Genetically meaningful phenotypic subgroups in autism spectrum disorders
Veatch OJ, Veenstra-Vanderweele J, Potter M, Pericak-Vance MA, Haines JL.

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

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?

CNVs conferring risk of autism or schizophrenia affect cognition in controls

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

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Patches of disorganization in the neocortex of children with autism
Q3. What caused this to happen and can it be prevented?

**The Journal of Pediatrics**

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**

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

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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
Q4. Which treatments and interventions will help?

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.

Two to Ten Years: Developmental Trajectories of Joint Attention in Children With ASD Who Received Targeted Social Communication Interventions
Gulsrud AC, Hellemann GS, Freeman SF, Kasari C.

These slides do not reflect decisions of the IACC and are for discussion purposes only.
Mitigation of sociocommunicational deficits of autism through oxytocin-induced recovery of medial prefrontal activity: a randomized trial

Q5. Where can I turn for services?

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.

March 1, 2014

Economic burden of childhood autism spectrum disorders
Lavelle TA, Weinstein MC, Newhouse JP, Munir K, Kuhlthau KA, Prosser LA.

March 2014
Q6. What does the future hold, particularly for adults?

Cognitive and language skills in adults with autism: a 40-year follow-up
Howlin P, Savage S, Moss P, Tempier A, Rutter M.

Employment outcomes of transition-aged adults with autism spectrum disorders: a state of the States report
Burgess S, Cimera RE.

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


March 28, 2014

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Transcriptional landscape of the prenatal human brain.
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)

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Centers for Disease Control Prevalence

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

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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
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 ADDM 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**

**Color Legend**
- Teal: Autism
- Magenta: Autism, Cerebral Palsy
- Orange: Autism, Intellectual Disability
- Green: 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

All children receiving services at participating health and education programs in the community

Children served under select diagnostic or eligibility categories at these community programs

Children identified as meeting surveillance case definition for ASD

All children with ASD living in the community
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

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

ASD Prevalence per 1,000 8-year-old Children

ADDMM Site

- Alabama
- Arizona
- Arkansas
- Colorado
- Georgia
- Maryland
- Missouri
- New Jersey
- N. Carolina
- Utah
- Wisconsin

ADDMM 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

Sites relying primarily on data from health-care sources
Sites with increased access to children's education records
Prevalence for All Sites Combined
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 ≤ 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 ≥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)

<table>
<thead>
<tr>
<th>Subtype of Earliest Diagnosis:</th>
<th>Autistic Disorder</th>
<th>ASD/PDD</th>
<th>Asperger Disorder</th>
</tr>
</thead>
<tbody>
<tr>
<td>Distribution of Subtypes:</td>
<td>43%</td>
<td>46%</td>
<td>11%</td>
</tr>
<tr>
<td>Median Age of Earliest Diagnosis:</td>
<td>48 Months</td>
<td>50 Months</td>
<td>74 Months</td>
</tr>
</tbody>
</table>

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

N = 337,093  N = 308,038

Number of Children

Age (mos)

0 20 40 60 80 100 120

2002  2006  Surveillance Year  2008  2010

N = 407,578  N = 308,038  8yo Population  N = 337,093  N = 363,749
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
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

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Community Report on Autism

To download a copy of the Community Report, please visit www.cdc.gov/autism
More Than Just A Number...

- Provides a more complete picture of autism
- Informs early identification efforts
- CDC’s Autism Tracking
- Helps identify potential risk factors
- Guides our research and the research of other scientists
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)

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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 included.
- 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”.

![Screening Passport Image]
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
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)

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Meeting of the IACC

Break

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The BRAIN Initiative

Story Landis, Ph.D.
Director
National Institute of Neurological Disorders and Stroke (NINDS)

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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
“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.”

~President Obama, April 2, 2013
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 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
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

5. **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
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: DARPA
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
The BRAIN Initiative℠ 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)

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

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

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

US Army Medical Research and Materiel Command
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
DoD ARP:
History and Background

FY07 $7.5 M
115 awards

$47.4 M

US Army Medical Research and Materiel Command
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
DoD ARP

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?**

- **Concept**
- **EHDA***
- **Pilot**

- **Early**
  - Concept
  - EHDA*
  - Pilot

- **Developing**
  - Idea Development

- **Clinical/Translational**
  - Clinical Trial

*Exploration – Hypothesis Development Award*
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

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<th>Question 1</th>
<th>When should I be concerned?</th>
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<td>Question 2</td>
<td>How can I understand what is happening?</td>
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<tr>
<td>Question 3</td>
<td>What caused this to happen and can it be prevented?</td>
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<tr>
<td>Question 4</td>
<td>Which treatments and interventions will help?</td>
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<tr>
<td>Question 5</td>
<td>Where can I turn for services?</td>
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<tr>
<td>Question 6</td>
<td>What does the future hold, particularly for adults?</td>
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<tr>
<td>Question 7</td>
<td>What other infrastructure and surveillance needs must be met?</td>
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</table>
FY07-FY12 ARP Portfolio
Percentage of Funds Invested per IACC Question

- Question 1: 20.1%
- Question 2: 32.2%
- Question 3: 27.7%
- Question 4: 7.1%
- Question 5: 0.4%
- Question 6: 0.3%
- Question 7: 12.2%
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
Systematic Characterization of the Immune Response to Gluten and Casein in ASD

Proteomic Mapping of the Immune Response to Gluten in Children with ASD
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
<table>
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<tr>
<td>Autism and Obesity: Co-Occurring Conditions or Drug Side Effects?</td>
<td>Zohreh Talebizadeh, Children’s Mercy Hospitals and Clinics</td>
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<td>Mobile Device-Prompted Workplace Culture Analysis, Self-Efficacy, and Anxiety Reduction in the Transition to Independent Employment for Individuals with ASD</td>
<td>David Hagner, University of New Hampshire</td>
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<td>Circadian Rhythms in Children with ASD and Their Infant Siblings</td>
<td>Marc Taylor, Naval Medical Research Center</td>
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<td>Imaging Depression in Adults with ASD</td>
<td>Kenneth Gaddow, State University of New York, Stony Brook</td>
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<td>Implicit Learning Abilities Predict Treatment Response in ASD</td>
<td>Catherine Lord, Cornell University, Weill Medical College</td>
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<td>Placental Identification and Immune Quantification of Acute and/or Chronic Inflammation in Children Diagnosed with ASD in University and Community Hospitals</td>
<td>Carolyn Salafia, Research Foundation for Mental Hygiene, Inc., Staten Island</td>
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DoD Defense Health Program
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

US Army Medical Research and Materiel Command
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

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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)

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

NDAR National Database for Autism Research
Serving the autism research community
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CPEA STAART ADOS G Module 4

ADOS G Module 4 as defined by the CPEA STAART project

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Description
Social Interaction Total

Value Range
No Restriction

Notes
None Provided

*112 subjects have no value provided for scoresumm_btotal

Filters
No filters currently applied. Click bar on chart to add filter.
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
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**
- Female: 60,244
- Male: 34,537
- Other: 1,716
- Not Reported: 1,018

**Phenotypic**
- Autism: 27,727
- Autism SI: 9,006
- Autism SI: 14,324
- Other: 8,710
- Not Defined: 23,729

**Neuroimaging**
- DTI: 1,423
- FMRI: 1,018
- MRI: 1,716
- Spectroscopy: 1,423
- EEG: 7,709

**Genomic**
- SNP and indels: 9,935
- Next Gen: 9,350
- Gene reg: 8,710
- Gene exp: 8,710
- Stem cell: 8,710
- Gene reg: 8,710
- Gene exp: 8,710
- STR Genotyping: 8,710
An Example of Data Associated with a Particular Laboratory

**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...

**Grant Information:**

<table>
<thead>
<tr>
<th>Project Number/Title</th>
<th>Start Date</th>
<th>End Date</th>
<th>Organization</th>
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<tr>
<td>P50HD55748</td>
<td>08/06/2007</td>
<td>07/31/2012</td>
<td>UNIVERSITY OF PITTSBURGH AT PITTSBURGH</td>
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**Publications** (Showing 3 of 39) Show All

- Bishop-Fitzpatrick, Lauren; Minshew, Nancy J; Eck, 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:**

<table>
<thead>
<tr>
<th>Title</th>
<th>Type</th>
<th>Number of Subjects</th>
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<tr>
<td>Autism Diagnostic Interview, Revised (ADI-R)</td>
<td>Clinical Assessments</td>
<td>212</td>
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<tr>
<td>Autism Diagnostic Observation Schedule - Module 1</td>
<td>Clinical Assessments</td>
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<td>Autism Diagnostic Observation Schedule - Module 4</td>
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<td>Benton Facial Recognition Test</td>
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<td>341</td>
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<td>CELF-4 Clinical Eval of Lang Fundamentals, 4th ed</td>
<td>Clinical Assessments</td>
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<td>CHARGE Family Characteristics Questionnaire</td>
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<td>CHARGE Physical Exam</td>
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Available Concepts (1 selected) Clear Selections Collapse All

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

General Parameters
- Age in Months From: 0 To: 1200
- Gender: Both

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

Concept:

Rules:
1. cbcl66 in (1:2)
2. rbwr_q18 between (1::3)
3. rbwr_q21 between (1::3)
4. rbwr_q22 between (1::3)
5. sd65 in (moderately; quite a bit; extremely;)
6. rbwr_q5 between (1::3)

Results in 750 subjects being discovered
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 Hessl 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
Teaching a Neurodiversity Course

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

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Teaching a Neurodiversity Course at College of William & Mary
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?
Meeting of the IACC

Lunch Break

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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

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Meeting of the IACC

Public Comments and Discussion

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Services Research for Autism Spectrum Disorder across the Lifespan

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

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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
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
“... 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

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ABLE Act of 2013

Stuart Spielman
Senior Policy Advisor and Counsel
Autism Speaks
• The ABLE 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.

• ABLE 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

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

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Meeting of the IACC

OARC Update

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

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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

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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."


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Preview: 2013 IACC Strategic Plan Update

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

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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?


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• 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

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](http://iacc.hhs.gov/reports/index.shtml)
Meeting of the IACC

Break

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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

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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

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Next IACC Meeting

July 8, 2014

6001 Executive Boulevard,
Neuroscience Center,
Conference Rooms C and D,
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Meeting of the IACC

Adjournment

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