Meeting of the Interagency Autism Coordinating Committee

July 19, 2011

Bethesda Marriott

5151 Pooks Hill Road

Bethesda, MD 20814

Conference Call Access:

Phone: (800) 369-1814

Access Code: 7791752

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Meeting of the IACC

Morning Agenda

10:00AM   **Call to Order and Opening Remarks**
Thomas Insel, M.D., Chair, IACC

10:05   **Review and Approval of April 11, 2011 Minutes**

10:10   **IACC Science Update**
Thomas Insel, M.D., Chair, IACC

10:30   **Autism Genetics**
Matthew W. State, M.D., Ph.D.

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Morning Agenda

11:00   **Convergence of Scientific Discoveries Enables Targeted Therapeutics for Individuals with Autism Spectrum Disorders**
Randall L. Carpenter, M.D.

11:30   **Break**

11:45   **Mortality in Autism and Epilepsy**
Geraldine Dawson, Ph.D.

12:00   **Lunch**

Meeting of the IACC

Morning Break

Meeting of the IACC

Lunch Break

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Open Session
for
Public Comment

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Afternoon Agenda

1:00   **Public Comments**

1:30   **ASD Outcomes in Adulthood**
Paul T. Shattuck, M.S., M.S.S.W., Ph.D.

2:00   **Trends in the Prevalence of Developmental Disabilities in US Children, 1997-2008**
Coleen Boyle, Ph.D., IACC Member

2:15   **Bullying and Students with Disabilities**
Ari Ne'eman, Vice Chair, Engagement, National Council on Disabilities and IACC Member

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Afternoon Agenda

Bullying and Students with Disabilities
Julia Bascom

2:45   **Diverse Needs in the Autism Community**
Heidi Scheer

The Needs of Adults with ASD
Scott M. Robertson

Break

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Afternoon Agenda – Cont'd

3:10   Break

3:30   Committee Business:

      - Safety Subcommittee Update
            Sharon Lewis, Co-Chair
            Lyn Redwood, R.N., M.S.N., Co-Chair
            Alison Singer, M.B.A., Co-Chair

            • **Update on IAN survey**
                  Paul A. Law, M.D., M.P.H.

            • **Update on ICD-9 Code**
                  Coleen Boyle, Ph.D., IACC Member

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Safety Subcommittee Update

Sharon Lewis
Co-Chair
Lyn Redwood, R.N., M.S.N.
Co-Chair
Alison Tepper Singer, M.B.A.
Co-Chair
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Committee Business (cont'd)

- **Services Subcommittee Update**
  Ellen Blackwell, M.S.W., Co-Chair
  Lee Grossman, Co-Chair

  - **Fall Services Workshop and Town Hall**

- **Update on Joint Activities of the Safety and Services Subcommittees**
  Ellen Blackwell, M.S.W., Co-Chair, Services
  Lee Grossman, Co-Chair, Services
  Sharon Lewis, Co-Chair, Safety
  Lyn Redwood, R.N., M.S.N., Co-Chair, Safety
  Alison Singer, M.B.A., Co-Chair, Safety

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Services Subcommittee Update

Ellen Blackwell, M.S.W.
Co-Chair
Lee Grossman
Co-Chair
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Services Subcommittee Activities

- Had a Joint Meeting of the Safety Subcommittee on May 19, 2011 to discuss seclusion and restraint

- IACC Services Workshop and Town Hall Meeting
  - September 15-16, 2011
  - Bethesda Marriott (Pooks Hill)

IACC Services Workshop and Town Hall Meeting

- September 15-16, 2011

- Bethesda Marriott (Pooks Hill)

- Will include a Town Hall Meeting

- Issue a report or take some other action as follow-up to this workshop and the one held on November 8, 2010

- Focus on maximizing opportunities and potential across the lifespan

Possible Topics for the IACC Services Workshop

- Self-determination and transition
- Employment and vocational opportunities for people with intellectual and developmental disabilities (ID/DD) – CMS perspective
- Managed care delivery systems – Pennsylvania Adult Community Autism Program (ACAP)
- Home and community-based services 101, including quality measurement and reporting
- Criminal justice diversion
- Department of Justice – Olmstead and the Americans with Disabilities Act enforcement and people with ID/DD

Possible Topics for the IACC Services Workshop (continued)

- Direct service certification - Department of Labor
- Private sector insurance support
- Recreational programs
- Family support
- Infrastructure
- Department of Defense programs
- Emergency preparedness
- National Background check program

Update on Joint Activities of the Safety and Services Subcommittee

Ellen Blackwell, M.S.W.
Co-Chair, Services Subcommittee
Lee Grossman
Co-Chair, Services Subcommittee
Sharon Lewis
Co-Chair, Safety Subcommittee
Lyn Redwood, R.N., M.S.N.
Co-Chair, Safety Subcommittee
Alison Singer, M.B.A.
Co-Chair, Safety Subcommittee
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Joint Safety and Services Subcommittee Meeting Activities

- Subcommittees met on May 19, 2011 to hear presentations and discuss seclusion and restraint (S/R)

- Presentations and video link available on IACC Website at www.iacc.hhs.gov

- In addition to educating the public and the IACC regarding S/R, the Subcommittees discussed drafting a letter to Secretary Sebelius on S/R

Summary of S/R Meeting Presentations

- Sharon Lewis, Co-Chair, Safety Subcommittee and Commissioner, Administration on Developmental Disabilities
  - Background on S/R
- Alexa Posny, Assistant Secretary for Special Education and Rehabilitative Services, U.S. Department of Education
  - Update on the Office of Special Education and Rehabilitative Services' activities to address S/R
- Ellen Blackwell, Co-Chair, Services Subcommittee, Centers for Medicare & Medicaid Services (CMS)
  - S/R in Medicaid
- Larke Huang, Senior Advisor on Children, Substance Abuse and Mental Health Services Administration (SAMHSA)
  - Alternatives to S/R

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Summary of S/R Meeting Presentations

- Chas Moseley, Associate Executive Director, National Association of State Directors of Developmental Disabilities

  - A Brief Look at State Policies and Practices

- Curt Decker, Executive Director, National Disability Rights Network

  - An Epidemic in Our Schools

- Bob Putnam, Senior Vice President, School Consultation, May Institute

  - Effective Implementation of School-Wide Positive Behavior Support: Reducing the Need for S/R

Joint Safety and Services Subcommittee Meeting

- The minutes and slides are an excellent summary of the status of this important issue across settings (schools, and community-based and institutional settings): http://iacc.hhs.gov/events/2011/joint-services-safety-subcommittee-mtg-slides-may19.shtml

- The Subcommittees worked together with Commissioner Lewis to draft a letter to Secretary Sebelius on S/R

- Discussion of draft letter

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- **Safety and Services Subcommittees – (cont'd)**
  - **Update on May 19, 2011 Joint Meeting on Seclusion and Restraint**
  - **DISCUSSION and VOTES: Letter to the Secretary on Seclusion and Restraint**

- **OARC Update**

  Susan A. Daniels, Ph.D., Acting Director, OARC and Executive Secretary, IACC
  - **Mid-Year Update on 2011 Summary of Advances**
  - **Portfolio Analysis update**

  Thomas Insel, M.D., Chair, IACC
  - **Update on Legislation & Status of the IACC**

Office of Autism Research Coordination Update

Susan A. Daniels, Ph.D.
Acting Director, OARC and Executive Secretary, IACC
IACC Full Committee Meeting – July 19, 2011

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2011 Summary of Advances

Mid-Year Installment

Self-Nomination Process:

- Nominations due **July 22, 2011** - Each IACC member will select and send to OARC the full citations of up to 5 articles he/she considers to be top advances in the field of autism biomedical and services research for calendar year 2011 (published only – does not include e-pub only articles).
- OARC will compile the full list of articles received.
- OARC will send the full list to the committee and provide instructions for voting in order to narrow the list down to 10 publications that can serve as the mid-year installment for top advances.

Final installment will be completed in early 2012

Portfolio Analysis Update

2009

- Final report is published on IACC website
- Data tables to be released on IACC website

2010

- Data call is ready to be sent
- Next steps are organizing and analyzing data
- Final step is preparing information for the IACC
- Plans for a companion analysis of ASD publications

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ASD Research Funders Solicited in 2009

Federal Funders of ASD Research

Centers for Disease Control and Prevention (CDC)

Centers for Medicare and Medicaid Services (CMS)

Department of Defense (DoD)

Department of Education (ED)

Health Resources and Services Administration (HRSA)

National Institutes of Health (NIH)

Possible additional funders to be included in 2010:

AHRQ, EPA, NSF, SAMHSA, ACF and Nancy Lurie Marks

Private Funders of ASD Research

Autism Science Foundation

Autism Speaks

Autism Research Institute (ARI)

Center for Autism and Related Disabilities

Organization for Autism Research (OAR)

Southwest Autism Research and Resource Center (SARRC)

The Simons Foundation (Simons)

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Legislative Update
July 2011

Thomas Insel, M.D.

Director, National Institute of Mental Health and Chair, IACC

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Legislative Update

- CAA reauthorization bills:
  - H.R. 2005 Combating Autism Reauthorization Act of 2011
  - S. 1094 Combating Autism Reauthorization Act

- Other autism legislation:
  - H.R. 2007 Autism Spectrum Disorders Services Act of 2011
  - S. 1132 Autism Spectrum Disorders Services Act of 2011
  - S. 850 Autism Services and Workforce Acceleration Act of 2011
  - H.R. 2006 National Autism Spectrum Disorders Initiative Act of 2011
  - S. 1128 National Autism Spectrum Disorders Initiative Act of 2011

Legislative Update

- Hearing before the House Energy and Commerce Health Subcommittee on July 11

    – Discussed H.R. 2005, the Combating Autism Reauthorization Act of 2011

- The IACC will sunset on September 30, 2011 unless new authorizing legislation is passed by Congress

    - Future meetings cannot be planned until new legislation is passed

    - If reauthorized, the Secretary can reappoint current IACC members or appoint new members

- If reauthorized, recognition of the service of current IACC members will take place at a future meeting

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Afternoon Agenda – Cont'd

4:30   Public Comments Discussion Period

5:00   Closing Comments and Adjournment

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Public Comments: Discussion Period

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Closing Comments and Adjournment