

IACC Strategic Planning Workgroup Meeting

April 21, 2008

Interagency Autism Coordinating Committee

**Neuroscience Center
Conference Room D
6001 Executive Boulevard
Rockville, MD 20850**

I. WHEN SHOULD I BE CONCERNED ABOUT MY CHILD'S DEVELOPMENT?

515 (12) I.C.2. Identify Relevant Phenotypes that Relate to Etiology, Symptom Presentation, and Outcome

360 (10) I.A.2. Collaborative Development of Streamlined Screening/Diagnostic Approaches

359 (12) I.A.3. Screening and Diagnostic Instruments in Underrepresented Populations

276 (11) I.C.1. The Development of Improved Categorical and Dimensional Measures of ASD

234 (9) 1.8.2. Characterizing and Improving the Diagnostic Process in the Community

234 (8) I.A.1. Predictive Validity of Existing Screens in Community Setting

120 (3) 1.8.1. Evaluating Diagnostic Criteria/Approaches

II. HOW CAN I UNDERSTAND WHAT IS HAPPENING TO MY CHILD?

- 381 (10) II.A.3.** Role of Immune and Infectious Factors in the Pathogenesis of Autism - Human and Animal Studies
- 333 (12) II.A.4.** Postmortem Brain and Tissue Acquisition Initiative
- 297 (11) II.B.2.** Developing Biomarkers for Autism
- 296 (9) II.A.1.** Multidisciplinary Longitudinal Study of Infants with Autism Before Age Three
- 263 (9) II.A.2.** Understanding Mechanisms of Neuroplasticity in Autism
- 220 (7) II.B.1.** Gender Differences in the Biological Features of Autism
- 145 (5) II.B.3.** Gene-based Phenotyping and Cognitive Neuroscience
- 108 (3) II.A.5.** Identification of Large-Scale Neural Systems Whose Function is Altered in Pre-adolescent Autism
- 45 (2) II.B.4.** New Paradigm for Clinical Genetic Evaluation and Subsequent Diagnosis

III. WHAT CAUSED THIS TO HAPPEN?

- 652 (17) III.B.3.** Analysis of Mechanisms Underlying the Interplay of Genetic and Environmental Factors
- 373 (11) III.B.5.** Develop Resources for Appropriate Control and Comparison Groups for Biological, Genetic and Other Studies of ASD
- 364 (14) III.B.2.** Studies of Risk Factor Exposures From Pre-Conception to Early Postnatal Life
- 230 (8) III.B.4.** Methods Development for Biologic Exposures I Biomarkers
- 208 (5) III.A.1.** Large-scale Resource of Genomic Data on Autism Spectrum Disorders
- 148 (5) III.B.1.** Risk Factor Studies in Other Special
- 124 (5) II.A.2.** Informing the Genetics and Neurobiology of ASD Based on New Heritable Phenotypes Populations

IV. WHICH TREATMENTS WILL HELP MY CHILD?

455 (13) IV.A.1. Interventions for Older Children and Adults with ASD

313 (9) IV.B.2. Investigation of Efficacy and Safety of Commonly Used and Untested Treatments for ASD

285 (9) IV.A.2. Intervention and Prevention Approaches for Infants and Toddlers at Risk for Autism

252 (7) IV.B.4. Fast Track Mechanisms to Facilitate Translational Treatment Research

211 (6) IV.B.3. Animal Models and Cellular Systems for Developing Treatments for Autism

195 (9) IV.B.1. Role of Co-morbidity in ASD Treatment

140 (6) IV.A.3. Efficacy Trials for Comprehensive Intervention Models for Individual with ASD Across Ages

98 (4) IV.C.2. Novel Treatments of Core Symptoms

48 (2) IV.C.1. Identification of Biomarkers to Guide Treatment Selection and Evaluation of Treatment Outcome

V. WHERE CAN I TURN FOR SERVICES?

623 (15) V.A.2. Identify and Evaluate Models of Effective Dissemination of Evidence-Based Practices (EBP) into Community Programs

568 (13) V.A.3. Evaluation of Community-Based Intervention Models Informed by MultiDisciplinary Best Practices

454 (11) V.A.4. Cost-Outcome Studies of Intervention Models for People with Autism Spectrum Disorder (ASD)

445 (1 0) V.A.1. State of the States for Individuals with Autism Spectrum Disorder (ASD)

VI. WHAT DOES THE FUTURE HOLD?

487 (12) VI.A.2. Improved Identification and Characterization of Autism in Adulthood

453 (13) VI.C.2. Develop Resources to Coordinate Large Population-Based ASD Initiatives (NDAR, CDC, NIH), IAN, State Registries)

436 (9) VI.A.1. Understanding Developmental Trajectories of Children and Families Affected by ASD

433 (9) VI.B.1. Enhance Tracking of ASD Prevalence in Children and Adolescents

291 (7) VI.C.1. Merging and Analyzing Administrative Databases Relevant to Diagnosis, Course, Interventions, and Long-Term Outcomes

"SEC. 399CC. INTERAGENCY AUTISM COORDINATING COMMITTEE.

“(a) ESTABLISHMENT – The Secretary shall establish a committee, to be known as the ‘Interagency Autism Coordinating Committee’ (in this section referred to as the ‘Committee’), to coordinate all efforts within the Department of Health and Human Services concerning autism spectrum disorder.



"SEC. 399CC. INTERAGENCY AUTISM COORDINATING COMMITTEE.

42 USC 280i-2.

“(a) ESTABLISHMENT – The Secretary shall establish a committee, to be known as the ‘Interagency Autism Coordinating Committee’ (in this section referred to as the ‘Committee’), to coordinate all efforts within the Department of Health and Human Services concerning autism spectrum disorder.

“(b) RESPONSIBILITIES – In carrying out its duties under this section, the Committee shall –

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

“(2) monitor Federal activities with respect to autism spectrum disorder;

“(3) make recommendations to the Secretary regarding any appropriate changes to such activities, including recommendations to the Director of NIH with respect to the strategic plan developed under paragraph (5);

“(4) make recommendations to the Secretary regarding public participation in decisions relating to autism spectrum disorder;

“(5) develop and annually update a strategic plan for the conduct of, and support for, autism spectrum disorder research including proposed budgetary requirements; and

“(6) submit to the Congress such strategic plan and any updates to such plan

Strategic plan

BUDGETARY REQUIREMENTS

- Need to look at international data re: exposures
- Use "other" category
- Need new strategy to be able to take advantage of recent advances
- Use "other" category with more creativity
- No new money associated with CAA
- Strategic planning helps attract more & better applications, eventually demands more dollars

COMMENTS ON SCORES

- Would have liked to score across 6 Qs
- Present to IACC - only initiatives that received the highest
- Intra paragraphs about initiatives to give context (not just titles and score)
- Some that score low seem related to others that scored higher
- Overlap is instructive

Next Steps:

- Assume WG will live on
- Use email to send in comments about overlap

Totals last updated 5-2-08, 12:00 p.m.