



Update on IACC Strategic Planning Process Steps

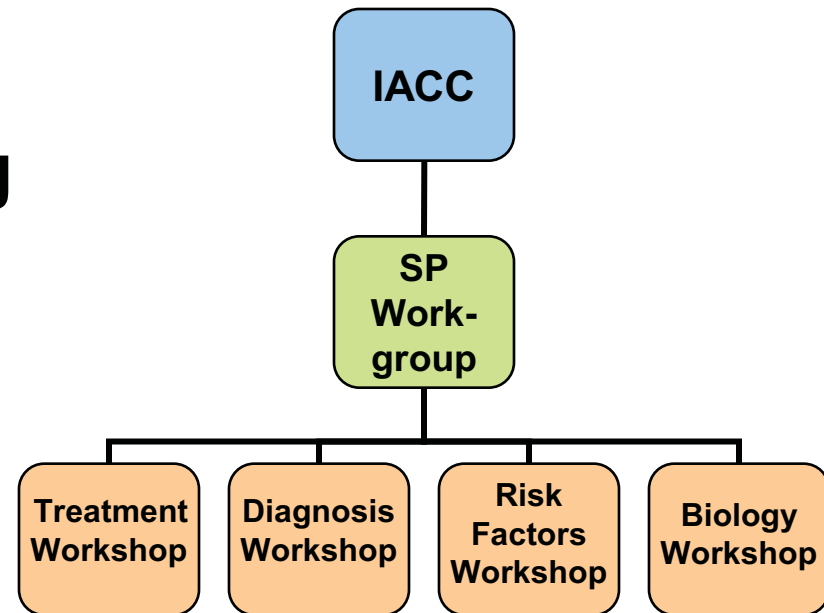


**Interagency Autism Coordinating
Committee Meeting
March 14, 2008**

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

Structure for Strategic Plan

- **IACC**
- **Strategic Planning (SP) Workgroup**
- **Scientific Workshops**



All involve

- **Stakeholders**
- **NIMH Autism Team**

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

Completed Steps

**IACC Approved Strategic Planning
Process – Nov 2007**

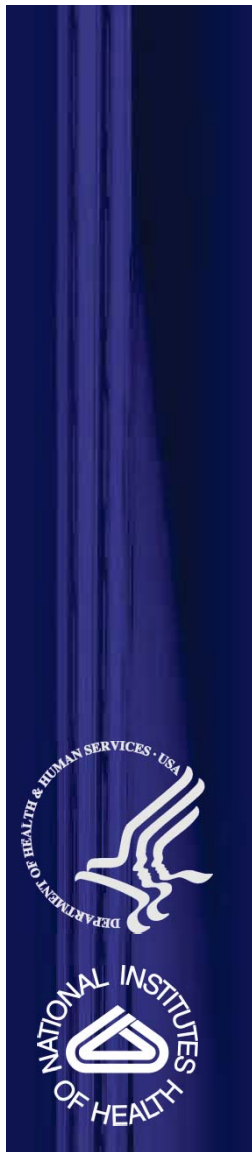
**Strategic Planning (SP) Workgroup
Formed – Dec 2007**

**Stakeholder RFI on ASD Research
Priorities –Dec 2007- Jan 2008**

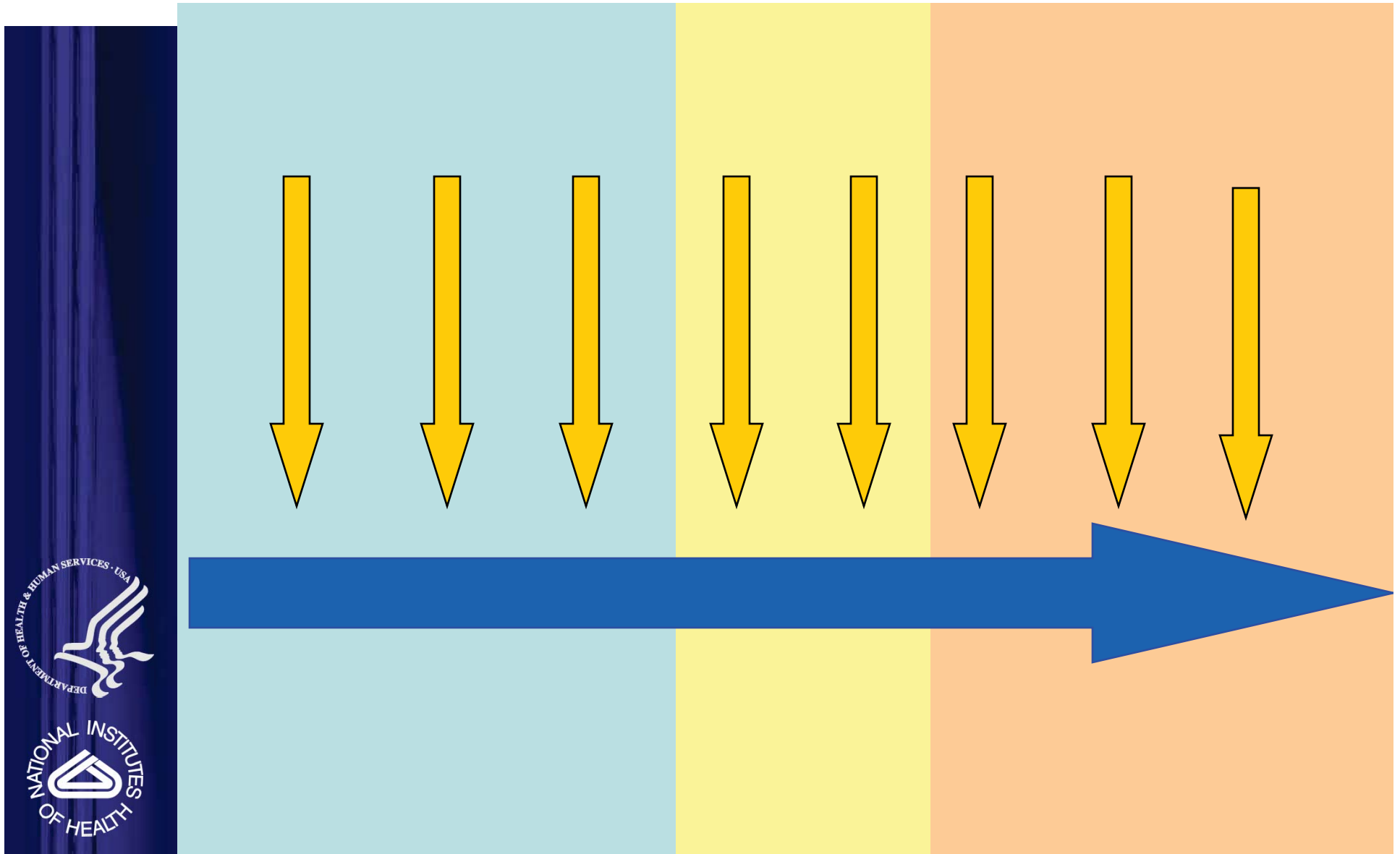
Four Scientific Workshops – Jan 2008

SP Workgroup Meeting – Feb 2008

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



Timeline for Strategic Plan for ASD Research



Stakeholder RFI

- **Research Priorities for the Interagency Autism Coordinating Committee (IACC) Strategic Plan for Autism Spectrum Disorders (ASD) – NOT-MH-08-003**
- **Purpose: to seek input from ASD stakeholders about high-priority research questions as a first step in receiving broad input at the beginning stages of strategic plan development**

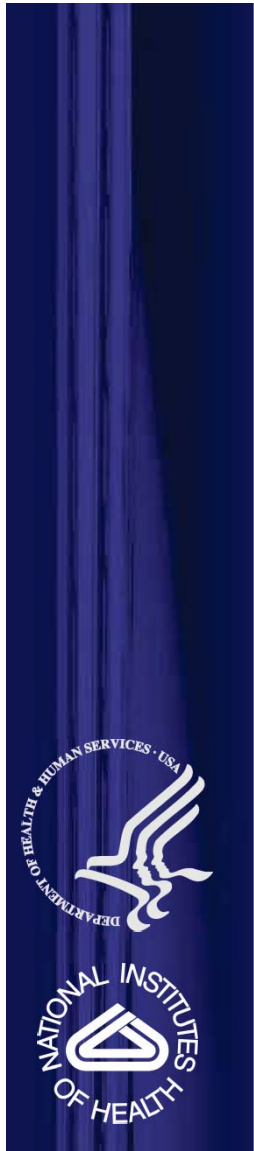


These slides do not reflect decisions of the IACC, they are for discussion purposes only.

Dissemination of RFI

- **RFI posted in NIH Guide Dec. 19, 2007**
- **Responses accepted through Jan. 4, 2008**
- **The link to RFI sent out electronically to a wide range of advocacy, research and professional organizations, NIH autism listserv and IACC members**
- **Phone calls made to key organizations asking to post RFI on their websites and/or to disseminate it to their membership.**

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



RFI Respondents

542 responses were received: many respondents provided personal information

Types of respondents:

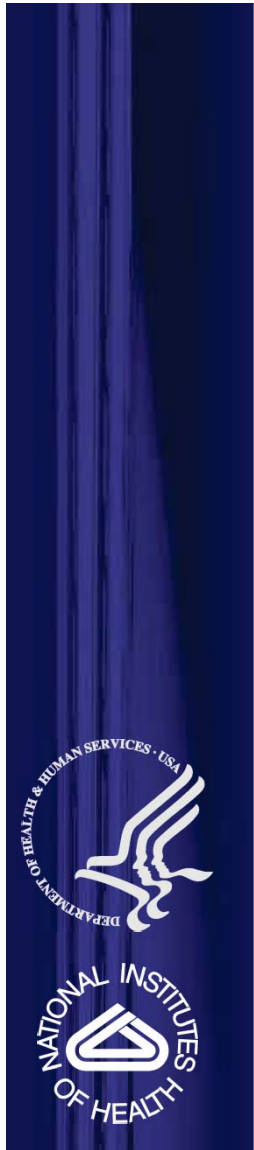
Parents or relatives of child with an ASD

Individuals self-identified with an ASD

Professionals involved in ASD care

Educators and school staff

Researchers in ASD and other fields



Institutional Affiliations

- **State autism societies**
- **State or local departments of health, mental health and public health**
- **University departments**
- **Disease-specific foundations**
- **Advocacy organizations**
- **Professional organizations**

Note: The recommendations from individuals did not substantially differ in terms of themes and tenor from those submitted by organizations

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



Geographic Distribution

- **RFI responses were received from nearly every U.S. state**
- **Military families**
- **Foreign countries such as Canada, England, Norway, Argentina, and France**



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

RFI responses

- **Treatment domain received the most responses**
- **Great diversity of opinions, some from completely opposite viewpoints**
- **Many personal stories were shared**
- **Generally very strong support for the need for more research on ASD**
- **Summaries of responses were provided to scientific workshops**



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

RFI Summaries

Summaries were written by a professional science writer using the following procedure:

- **Each RFI response was read completely**
- **Any research recommendation was identified, and excerpted by cutting and pasting**
- **No attempt was made to quantify responses or estimate the frequency of a particular recommendation**
- **Overall intent was to include all ideas and thereby create a broad listing of recommendations loosely organized along subtopics**

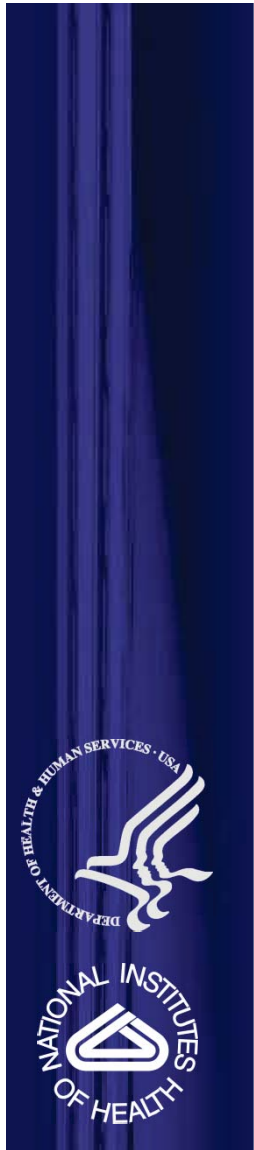
These slides do not reflect decisions of the IACC, they are for discussion purposes only.



Scientific Workshops

- **Domains of Biology, Treatment ,
Diagnosis, Risk factors**
- **Held on four consecutive days to
provide some overlap and carry over
between workshops**
- **Provided RFI summaries; research
accomplishments and resources from
government and private ASD funding
organizations**
- **Used a template to generate high priority
research initiatives**

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



Workshop participants

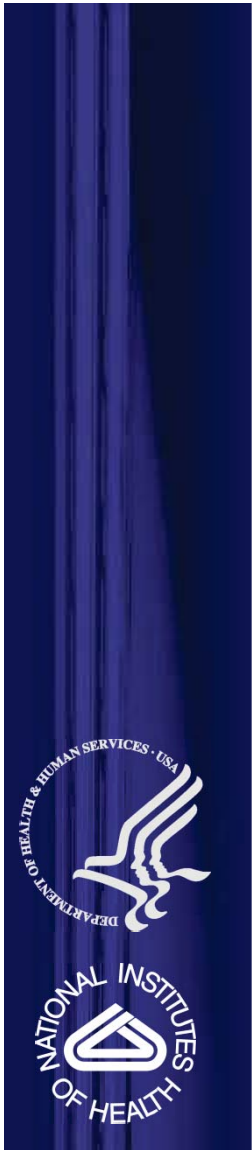
Workshop chairs were selected in advance (Amaral, Dawson, Lord, Geschwind)

Nominations solicited from IACC, SP workgroup, program staff at NIH and CDC

Workshop chairs reviewed nominees

SP Workgroup formed groups that balanced scientific representation with diverse stakeholder viewpoints

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



Biology Workshop

- **The underlying biological processes that lead to developmental and medical problems associated with ASD.**
- **This includes research in the area of neurosciences but does not confine itself to neurosciences. Therefore, research on other organ systems, interactions between organ systems, and/or other disease processes are included in this area.**

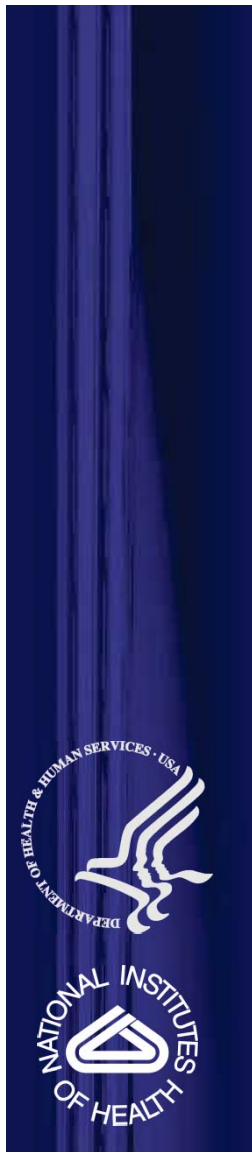


These slides do not reflect decisions of the IACC, they are for discussion purposes only.

Biology Workshop (14)

- **David Amaral, Ph.D. – Chair** (UC Davis)
- Anthony Bailey, M.B.B.S. (Univ. of Oxford)
- Patrick Bolton, Ph.D. (Inst. of Psychiatry, London)
- Eric Courchesne, Ph.D. (UCSD)
- Jacqueline Crawley, Ph.D. (NIMH)
- Martha Herbert, M.D., Ph.D. (Harvard)
- Peter Hotez, M.D., Ph.D. (Geo Washington U)
- Allan Jones, Ph.D. (Allen Inst for Brain Science)
- A. Kimberley McAllister, PhD. (UC Davis)
- Valerie Paradiz, Ph.D
- Carlos Pardo-Villamizar, M.D. (Johns Hopkins)
- Robert Schultz, Ph.D. (Child Hosp Philadelphia)
- Susan Swedo, M.D. (NIMH)
- Judy Van de Water, Ph.D. (UC Davis)

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



Treatment Workshop

- **Includes ASD treatment, intervention, and services research that aim to reduce symptoms, promote development, and improve outcomes.**
- **This area includes the development and evaluation of medical, behavioral, educational, and complementary interventions for ASD.**
- **In addition, this area includes research studies that evaluate the effectiveness of treatments in real world settings, disparities in ASD treatment among specific subpopulations, practice patterns in ASD programs and services, and their cost-effectiveness.**

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





Treatment Workshop (18)

- **Geraldine Dawson, Ph.D. – Chair** (U Washington)
- Margaret Bauman, M.D. (Harvard)
- Ellen Blackwell, M.S.W. (CMS)
- Tony Charman, Ph.D. (University College London)
- James Conroy, Ph.D. (Center for Outcome Analysis)
- Charles Gordon, M.D.
- William Greenough, Ph.D. (University of Illinois)
- Lee Grossman (Autism Society of America)
- Eric Hollander (Mount Sinai School of Medicine)
- Bryan Jepson, M.D. (Thoughtful House)
- James Laidler, M.D. (Portland State University)
- David Mandell, Sc.D. (University of Pennsylvania)
- Brenda Myles, Ph.D. (University of Kansas)
- Samuel Odom, Ph.D. (University of North Carolina)
- Lyn Redwood MSN (SafeMinds)
- Tristram Smith, Ph.D. (University of Rochester)
- Sarah Spence (NIMH)
- Aubyn Stahmer, Ph.D. (UCSD)



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

Diagnosis Workshop

- **This area is concerned with the accurate and valid description and measurement of ASD (phenotype) both at the individual and the population level.**
- **The public health impact of ASD can be better understood by such studies.**
- **In addition, this area concerns itself with the diversity of what constitutes ASD and the characteristics of the condition over the lifespan.**

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



Diagnosis Workshop (16)

- **Catherine Lord, Ph.D. – Chair** (Univ. Michigan)
- Tony Charman, Ph.D. (University College London)
- John Constantino, M.D. (Washington University)
- Vicky Debold, Ph.D., R.N. (SafeMinds)
- Wolf Dunaway (Social Security Administration)
- Peter Gerhardt, Ed.D. (Org Autism Research)
- Yvette Janvier, M.D. (Children's Specialized Hosp)
- Peter Mundy, Ph.D. (UC Davis)
- Craig Newschaffer, Ph.D. (Drexel University)
- Karen Pierce, Ph.D. (UCSD)
- Catherine Rice, Ph.D. (CDC)
- Paul Shattuck, Ph.D. (Washington University)
- Christopher Smith, Ph.D. (SARRC)
- Peter Szatmari, M.D. (McMaster University)
- Edwin Trevathan, M.D., M.P.H. (CDC)
- Fred Volkmar, M.D. (Yale University)



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

Risk Factor Workshop

- **Investigations of the factors that contribute to the risk of having an ASD in a given person or population.**
- **This includes genetic studies of clusters or sporadic occurrences of ASD, studies that focus on environmental factors, e.g. intrauterine events or exposure to toxins, which could lead to ASD, and the interaction between these factors that concentrate risk for ASD.**

Risk Factors Workshop (14)

- **Daniel Geschwind, M.D., Ph.D. – Chair (UCLA)**
- Laura Bono (SafeMinds)
- Maja Bucan, Ph.D. (University of Pennsylvania)
- Lisa Croen, Ph.D. (Kaiser Permanente)
- Cindy Lawler, Ph.D. (NIEHS)
- David Ledbetter, Ph.D. (Emory University)
- Eric London, M.D. (Inst Basic Research Dev'l Dis)
- Craig Newschaffer, Ph.D. (Drexel University)
- Isaac Pessah, Ph.D. (UC Davis)
- Joseph Piven, M.D. (UNC)
- Matthew State, M.D., Ph.D. (Yale University)
- Ezra Susser, M.D., Dr. P.H. (Columbia University)
- Edwin Trevathan, M.D., M.P.H. (CDC)
- Christopher Walsh, M.D., Ph.D. (Harvard)

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

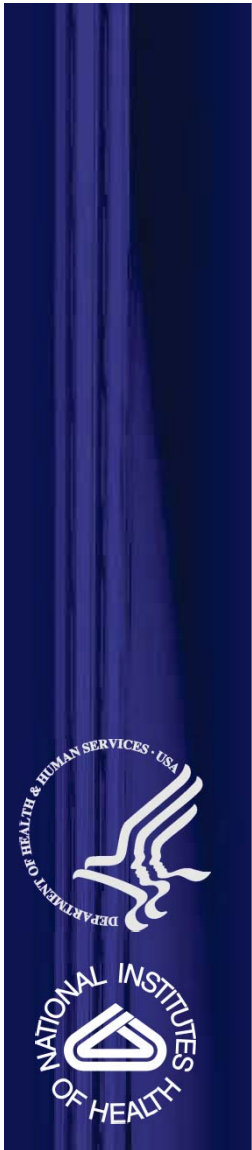


SP Workgroup

Thomas Insel - Chair
David Amaral*
Peter Bell – Autism Speaks
Geraldine Dawson*
Daniel Geschwind*
Gerald Fischbach – Simons Foundation
Cathy Lord*
Craig Newschaffer – Drexel University
Denise Resnick - SARRC
Ed Trevathan - CDC
Ann Wagner – NIH

*** workshop chair**

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



SP Workgroup Meeting

- **Discussed the workshops and the 41 research initiatives**
- **Began to generate guiding principles for the strategic plan**
- **Proposed a framework for organizing the research initiatives**
- **Considered areas that were missing from the initiatives that came from the workshops**

Framework for Initiatives

1. **When** should I be concerned about my child's development? (7)
2. **How** can I understand what is happening to my child? (9)
3. **Why** did this happen? (7)
4. **Which** treatments will help my child? (9)
5. **Where** can I turn for services? (4)
6. **What** does the future hold? (4)

When should I be concerned about my child's development?

What are the early warning signs (red flags) that something might be going on?

Are there typical characteristics that are part of an ASD diagnosis?

How much variation is there in symptoms and severity associated with ASD?

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





When should I be concerned about my child's development?

Predictive Validity of Existing Screens in Community Settings: Assessing Effectiveness and Efficacy

Collaborative Development of Streamlined Screening/Diagnosis Approaches to Support Large-Scale Genetic Population-based Studies

Evaluating Diagnostic Criteria/Approaches

Characterizing and Improving the Diagnostic Process in the Community

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





When should I be concerned about my child's development?

The Development of Improved Categorical and Dimensional Measures of ASD, Associated Features, and the Broader Autism Phenotype, Relevant to Diagnosis, Severity, Outcome and Treatment and Pharmacologic Response

Screening and Diagnostic Instruments in Minority or Disadvantaged or Underrepresented Populations

Identify Relevant Phenotypes That Relate to Etiology, Symptom Presentation, and Outcome

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



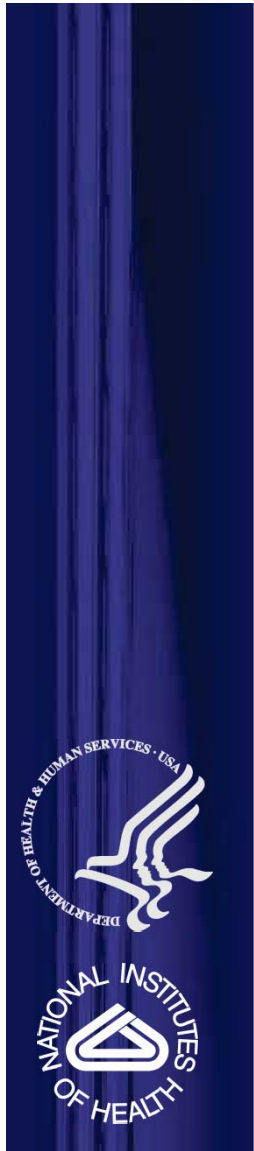
How can I understand what is happening to my child?

What could be happening early in development?

Are there known biological differences that help define ASD?

Are there subgroups of people with ASD that have been identified?

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



How can I understand what is happening to my child?

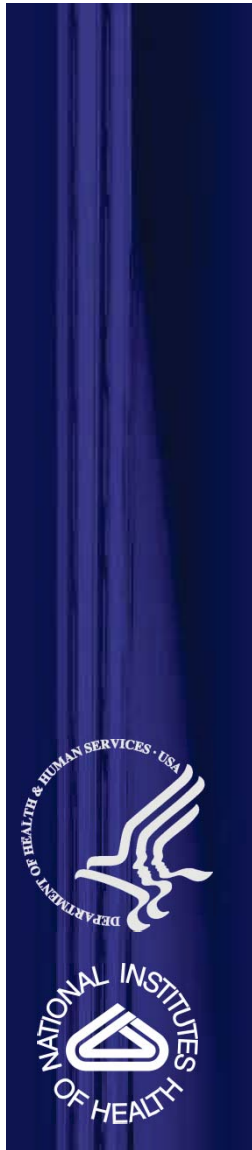
Multidisciplinary Longitudinal Study of Infants with Autism Before Age Three

Understanding Mechanisms of Neuroplasticity in Autism

Gender Differences in the Biological Features of Autism

Role of Immune and Infectious factors in the Pathogenesis of Autism - Human and Animal Studies

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



How can I understand what is happening to my child?

Postmortem Brain and Tissue Acquisition Initiative

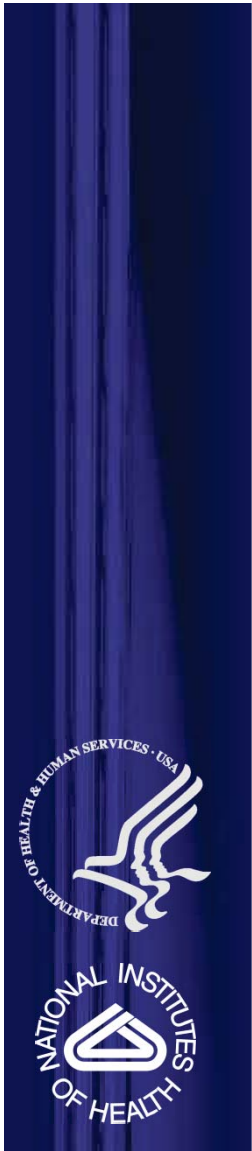
Developing Biomarkers for Autism

Gene-based Phenotyping and Cognitive Neuroscience

New Paradigm for Clinical Genetic Evaluation and Subsequent Diagnosis

Identification of Large-Scale Neural Systems Whose Function is Altered in Pre-Adolescent Autism

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



Why did this happen?

Is there something in my personal or family history that poses a risk for ASD?

How might genetics and/or the environment influence the occurrence of ASD?

Do we know how to detect possible causes of ASD?

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



Why did this happen?

Large-Scale Resource of Genomic Data on Autism Spectrum Disorders

Risk Factor Studies in Other Special Populations with Unique Well-Characterized Features

Risk Factor Studies Focusing on Pre-Conception, Prenatal, Perinatal, and Early Postnatal Prediagnostic Exposures

Analysis of Mechanisms Underlying the Interplay of Genetic and Environmental Factors

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



Why did this happen?

Methods Development for Biologic Exposures / Biomarkers

Informing the Genetics and Neurobiology of Autism Spectrum Disorders and Related Disorders Based on New Heritable Phenotypes

Develop Resources for Appropriate Control and Comparison Groups for Biological, Genetic and Other Studies of ASD, Including Specimens Most Relevant to Environmental Exposure and Perform Research Studies to Compare and Contrast These Groups

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



Which treatments will help my child?

When do I start treatment or interventions?

What do we know makes a difference for those with ASD?

What are the medical or mental health issues I need to know about?

How do I know that treatments are both safe and effective?

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





Which treatments will help my child?

Interventions for Older Children and Adults with ASD

Intervention and Prevention Approaches for Infants and Toddlers at Risk for Autism

Efficacy Trials for Comprehensive Intervention Models for Individuals with ASD Across Ages

Identification of Biomarkers to Guide Treatment Selection and Evaluation of Treatment Outcome in Individuals with ASD

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





Which treatments will help my child?

The Role of Co-morbidity in ASD Treatment

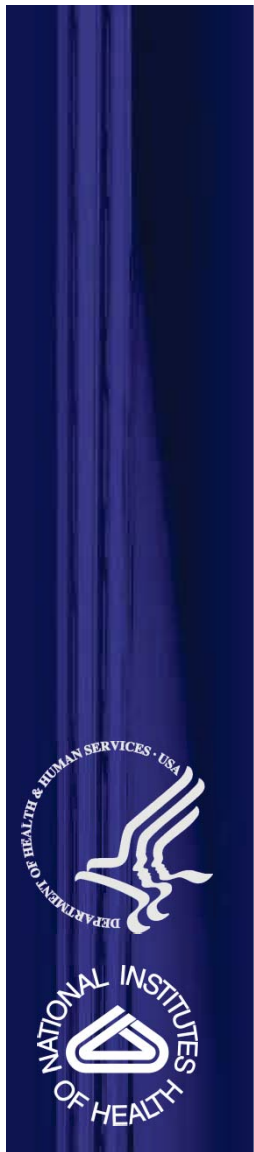
Novel Treatments for Core Symptoms

Investigation of Efficacy and Safety of Commonly Used and Untested Treatments for Autism Spectrum Disorders

Animal Models and Cellular Systems for Developing Treatments for Autism

Fast Track Mechanisms to Facilitate Translational Treatment Research

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



Where can I turn for services?

What types of services should I seek and where should I seek them?

What is my state or local government doing to provide services for ASD?

What is the cost of treatment and how will it be paid?

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



Where can I turn for services?

State of the States for Individuals with Autism Spectrum Disorder (ASD)

Identify and Evaluate Models of Effective Dissemination of Evidence-Based Practices (EBP) into Community Programs

Evaluation of Community-Based Intervention Models Informed by Multi-Disciplinary Best Practices

Cost-Outcome Studies of Intervention Models for People with Autism Spectrum Disorder (ASD)

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



What does the future hold?

What will my child be like when he/she gets older?

How can I plan for when my child is a teenager or adult?

How can society support individuals with ASD?

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



What does the future hold?

Understanding Development Trajectories of Children and Families Affected by ASD

Improved Identification and Characterization of Autism in Adulthood

Enhance Tracking of ASD Prevalence in Children and Adolescents

Merging and Analyzing Administrative Databases Relevant to Diagnosis, Course, Interventions, and Long-Term Outcomes

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



Next Steps

The strategic planning process will be reviewed by the IACC and decisions need to be made about steps going forward

IACC website will be updated to include summaries of the completed steps of the planning process

Autism Team would like IACC permission to initiate writing sections of the SP and summary of advances in ASD research

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

