

**Interagency Autism Coordinating Committee (IACC)  
Strategic Plan for Autism Spectrum Disorders Research  
Status Report  
May 2008**

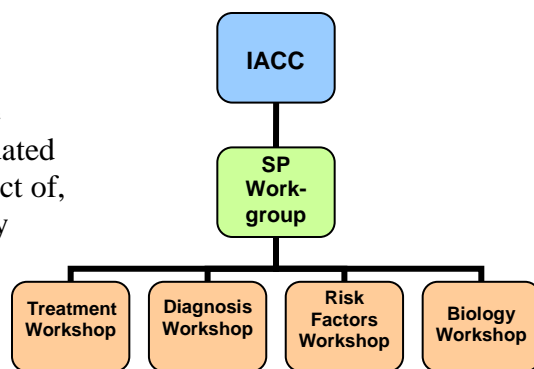
**Strategic Planning Process:**

At its inaugural meeting in November 2007, the IACC approved a process for developing the initial version of the Strategic Plan for Autism Spectrum Disorder (ASD) Research required by the Combating Autism Act of 2006. This process will result in a strategic plan based on a prioritized set of research initiatives to be implemented over the next several years and updated annually. It incorporates several opportunities for public input, the formation of a strategic planning (SP) workgroup and the convening of several scientific workshops.

**Structure for Strategic Planning:**

**Interagency Autism Coordinating Committee (IACC):**

The IACC is a federal advisory committee established by the Combating Autism Act of 2006 (CAA) and, as such, is mandated to develop and annually update a strategic plan for the conduct of, and support for, ASD research, including proposed budgetary requirements. In addition, the IACC has additional responsibilities to provide an annual summary of research advances in ASD, monitor Federal activities with respect to ASD, and make recommendations to the Secretary of the Department of Health and Human Services regarding public participation in decisions relating to ASD.



**Strategic Planning Workgroup (SP workgroup):**

Workgroups can be formed by federal advisory committees to work on time-limited tasks and provide additional expertise. A Strategic Planning (SP) workgroup was formed by the IACC to facilitate the development of the strategic plan. The workgroup is composed of researchers, advocates, program officials, clinicians and a subset of IACC members. The SP workgroup was charged with making recommendations to the IACC regarding research priorities for the strategic plan.

**Scientific Workshops:**

The SP workgroup organized scientific workshops to generate high priority research initiatives in four domains: Biology, Treatment, Diagnosis, and Risk Factors. The process for selecting workshop participants was overseen by the SP workgroup and workshop invitees were selected based on diverse viewpoints and expertise, with the goal of balance within groups. IACC members were given the option to nominate workshop participants, and participate or observe workshops.

All groups represented in the diagram above have stakeholder representation and are staffed by the NIMH Autism Team

## **Completed Steps of the Strategic Planning Process to Date:**

**Strategic Planning Process Approved by IACC** – November 30, 2007

**Strategic Planning (SP) Workgroup Formed** – December 12, 2007

**Stakeholder RFI on ASD Research Priorities** – December 19, 2007- January 4, 2008

**Four Scientific Workshops Held** – January 15-18, 2008

**First SP Workgroup Meeting** – February 21, 2008

**IACC Reviewed and Modified SP Process** – March 14, 2008

**Second SP Workgroup Meeting** – April 21, 2008

## **Description of Specific Steps in Planning Process:**

**I. Public Request for Information (RFI):** Research Priorities for the Interagency Autism Coordinating Committee (IACC) Strategic Plan for Autism Spectrum Disorders (ASD) – NOT-MH-08-003

**Purpose of RFI:** 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

- RFI posted in NIH Guide Dec. 19, 2007 - responses accepted through Jan. 4, 2008
- RFI link 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.

**Responses to RFI:** 542 responses were received

Types of individual 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

Types of organizational responses:

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

RFI responses were received from nearly every U.S. State, military families, and foreign countries such as Canada, England, Norway, Argentina, and France.

- 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

## **II. IACC Sponsored Scientific Workshops:**

A series of full-day scientific workshops were held January 15-18, 2008 that focused on one ASD research domain each day: Biology, Treatment, Diagnosis, and Risk Factors chaired by David Amaral, Geri Dawson, Cathy Lord, and Dan Geschwind respectively. Workshops were organized on successive days in order to build in overlap between some participants and facilitate discussions at the interface of workshop domains. In addition, workshops were encouraged to discuss the cross-cutting themes of heterogeneity and ASD trajectories.

There were sixty workshop participants over the four day period including domestic and international scientific experts, representatives from private autism funding organizations and advocacy groups, clinicians, individuals with ASD, and members of the IACC. There were also over 30 observers. To inform their deliberations, workshop participants reviewed research accomplishments and ongoing initiatives and resources for ASD research as reported by Federal agencies and private funding organizations. Another important input to the workshops was a comprehensive summary of the responses received from the public RFI. Workshops were asked to consider the strengths and weaknesses that comprise the current state of the science in the particular area, identify opportunities and questions still unanswered, as well as research resources needed to advance these questions. They then generated a number of proposed research initiatives. Workshop participants were asked to give highest consideration to research activities that would have the largest impact on the lives of individuals with ASD and their families.

### **Description of workshop domains:**

**Biology:** 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, or other disease processes are included in this area.

**Treatment:** ASD treatment, intervention, and services research that aim to reduce symptoms, promote development, and improve outcomes. This includes the development and evaluation of medical, behavioral, educational, and complementary interventions for ASD. In addition, 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 are included.

**Diagnosis:** 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.

**Risk Factors:** 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.

### **Workshop Products**

The key output of the workshops was a set of 41 research opportunities that were detailed using a specified template. Each initiative template provides information regarding the need to be addressed, the proposed solution, whether the proposal includes a new tool or a modification of an existing resource, impact, evaluation and timeframe. The impact section of the template includes a description of how the proposed activity will facilitate other research activities and what the contingencies will be regarding its initiation and completion. A section indicates how progress on the initiative would best be evaluated.

### **III. SP Workgroup Accomplishments:**

#### **First SP Workgroup Meeting** (February 2008):

Participants: Thomas Insel (chair), Dan Geschwind, David Amaral, Geri Dawson, Cathy Lord, Peter Bell, Gerald Fischbach, Ann Wagner, Edwin Trevathan, Craig Newschaffer, Denise Resnik

The goals for the SP workgroup meeting were to discuss the 41 research initiatives generated by workshops and to consider ideas that were missing from workshop initiatives. They also formulated guiding principles/values for the strategic plan, and proposed a framework for organizing the research initiatives. The values for the plan and a framework for opportunities are listed below and were approved by the IACC at its March 2008 meeting.

**Values** - shared principles to guide our actions

- **Sense of Urgency** – We will focus on what steps we can take now to be responsive to the needs of individuals and families affected by ASD.
- **Spirit of Collaboration** – We will treat others with respect, listen to diverse views with open minds, and foster discussions where participants can comfortably offer opposing opinions.
- **Consumer-focused** – We will focus on making a difference in the lives of people affected by ASD, including individuals with ASD, their families, medical practitioners, educators, and scientists.
- **Excellence** – We will pursue basic and clinical research of the highest quality to protect the safety and advance the best interests of those affected by ASD.
- **Partnerships in Action** – We will value cross-disciplinary approaches, data sharing, teamwork, and partnerships with clearly defined roles and responsibilities.
- **Accountability** – We will develop SMART (specific, measurable, achievable, realistic, and time-bound) research objectives aligned with funding priorities and develop systems for evaluation and course corrections.

### **Framework for Research Opportunities: (number of research initiatives)**

- 1. When should I be concerned about my child's development? (7)**
  - What are the early warnings signs 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?
- 2. How can I understand what is happening to my child? (9)**
  - What could be happening early in development?
  - Are there known biological differences that help explain why my child is having ASD symptoms?
  - Are there subgroups of people with ASD that have been identified?
- 3. What caused this to happen and can this be prevented? (7)**
  - Is there something in my genetic or family history that poses a risk for ASD?
  - How might genetics and/or the environment influence the occurrence of ASD?
  - Could my child or I have been exposed to something in the environment that led to the development of ASD?
- 4. Which treatments will help my child? (9)**
  - When do I start treatment or interventions?
  - What do we know makes a difference for those with ASD?
  - What are the medical issues I need to know about?
  - How do I know that treatments are both safe and effective?
- 5. Where can I turn for services? (4)**
  - 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?
- 6. What does the future hold? (5)**
  - What will my child be like when he/she gets older?
  - What is known about adults with ASD and how can I plan for the future?
  - How does society support individuals with ASD?

### **Second SP Workgroup Meeting (April 2008)**

Participants: Steve Hyman (chair), David Amaral, Peter Bell, Mark Blaxill, Judith Cooper, Geraldine Dawson, Steve Eiken, Daniel Geschwind, Martha Herbert, Alice Kau, Catherine Lord, David Mandell, Prisca Chen Marvin, Sam Odom, Isaac Pessah, Denise Resnik, Stephen Shore, Fan Tait, Edwin Trevathan, Andrew Zimmerman, Lucille Zeph

A new SP workgroup was formed by the IACC at its March meeting to broaden representation. Each IACC member either nominated a workgroup member or served on the workgroup; the four workshops chairs were asked to remain on the workgroup.

The NIMH Autism Team coordinated the compiling of 2007 ASD research funding portfolio information from major funding sources: NIH, CDC, DoD, Simons Foundation and Autism Speaks prior to the workgroup meeting. The team also solicited additional feedback from workshop participants as to whether ideas from the stakeholder RFI were included within research initiatives. This feedback was used to modify initiatives; no new initiatives were written.

The main goals for the second SP workgroup meeting were to: review the 2007 ASD research funding portfolio, prioritize research initiatives within the six question framework, and discuss budgetary requirements of the strategic plan.

**Issues for IACC discussion at May meeting:**

**Draft Vision** – what we aspire to achieve in the next five years:

*The Strategic Plan will accelerate and inspire research that will profoundly improve the health and well-being of every individual with an ASD across the lifespan.*

**Draft Mission** – our reason for doing a strategic plan for ASD research

*The purpose of the Strategic Plan is to focus, coordinate, and accelerate high quality research and scientific discovery to answer the urgent questions and needs of ASD individuals and families.*

**Draft Aspirational Goals:** within the six question framework

**WHEN should I be concerned about my child's development?**

*All children with ASD will be identified at an early age and receive care appropriate to diagnosis*

**HOW can I understand what is happening with my child?**

*Discovering how ASD affects development will lead to targeted and personalized treatments*

**WHAT caused this to happen and how can this be prevented?**

*Causes of ASD will be discovered that lead to prevention/preemption of ASD*

**WHICH treatments will help my child?**

*Best practices for treating children, adolescents and adults with ASD will be developed, tested and disseminated*

**WHERE can I turn for services?**

*Communities will implement high quality, evidence-based and cost effective ASD services across the lifespan*

**WHAT does the future hold?**

*Advances in treatment and public understanding will enable individuals on the autism spectrum to lead fulfilling and productive lives in the community*