

Overview of IACC Strategic Planning Process

**IACC Town Hall Meeting
May 3, 2008**



Structure for Strategic Planning



- **IACC – the parent body established by the Combating Autism Act of 2006 (CAA), mandated by CAA to develop and annually update a strategic plan for the conduct of and support for ASD research**

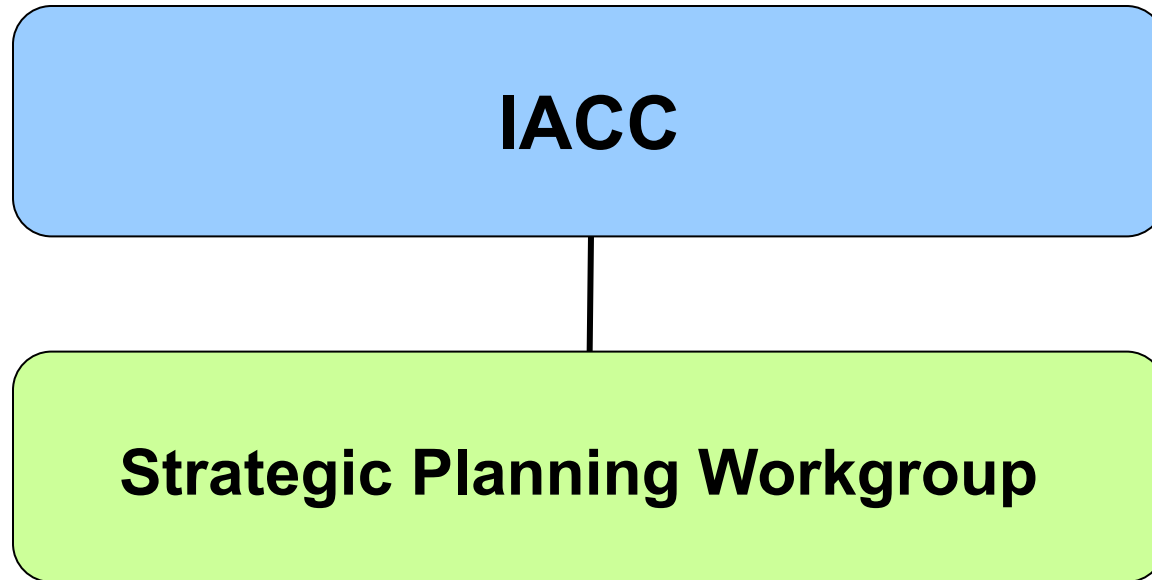
IACC Federal Members

- **Thomas Insel (NIMH) – chair**
- **Patricia Morrissey (ACF)**
- **Edwin Trevathan (CDC)**
- **Ellen Blackwell (CMS)**
- **Gail Houle (ED)**
- **Peter van Dyck (HRSA)**
- **Duane Alexander (NICHD)**
- **James Battey (NIDCD)**
- **Cindy Lawler (NIEHS)**
- **Story Landis (NINDS)**
- **Margaret Giannini (HHS Office on Disability)**
- **Larke Huang (SAMHSA)**

IACC Public Members

- **Lee Grossman (President and CEO, Autism Society of America)**
- **Yvette Janvier, M.D. (Medical Director, Children's Specialized Hospital, Tom's River, NJ)**
- **Christine McKee, J.D.**
- **Lyn Redwood, MSN (President, Coalition for SafeMinds)**
- **Stephen Shore, Ed.D. (Executive Director, Autism Spectrum Disorder Consulting)**
- **Alison Singer, MBA (Executive Vice-President, Autism Speaks)**

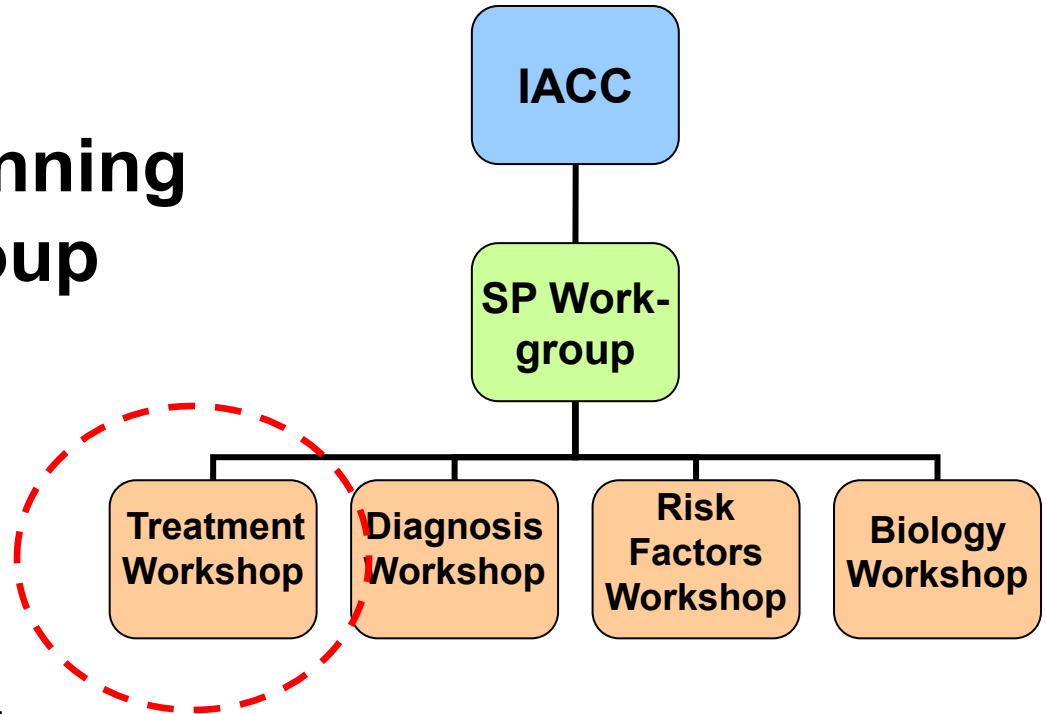
Structure for Strategic Planning



SP Workgroup – established by the IACC to facilitate the development of the strategic plan; workgroup provides additional expertise and includes representatives from a broad group of stakeholders

Structure for Strategic Plan

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



All involve

- Stakeholders
- NIMH Autism Team

Completed Steps

**Strategic Planning Process Approved
by IACC – Nov 07**

**Stakeholder Request for Information
(RFI) – Dec 07- Jan 08**

**Four Scientific Workshops Held – Jan
08**

SP Workgroup Meeting – Feb 08

New SP Workgroup Meeting– April 08

Stakeholder RFI

- **Purpose: to seek input from ASD stakeholders about research priorities as a first step in receiving broad input at the beginning stages of strategic planning development**
- **RFI link sent out electronically to advocacy, research and professional organizations, NIH autism listserv and IACC members**

RFI Responses

542 responses received from across the US, military families and foreign countries

Many from parents, relatives, individuals self-identified with ASD; professionals, educators and researchers involved with ASD; advocacy and professional organizations, health departments, universities, and foundations

Scientific Workshops

- **Divided into Biology, Treatment , Diagnosis, Risk Factors workshops**
- **Held on 4 consecutive days for overlap and carry over between workshops**
- **Given RFI summaries; research accomplishments and resources from government and private ASD funding organizations**
- **Used a template to generate research initiatives**

SP Workgroup Meetings

- **Discussed the 41 research initiatives generated by workshops**
- **Formulated guiding principles/values for the strategic plan**
- **Proposed a framework for organizing the research initiatives that was consumer oriented**
- **Considered areas that were missing from workshop initiatives**

Values for IACC Strategic Plan

(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.

Values

- **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 Initiatives

- I. **When** should I be concerned about my child's development? (7)
- II. **How** can I understand what is happening to my child? (9)
- III. **What** caused this to happen and how can we prevent? (7)
- IV. **Which** treatments will help my child? (9)
- V. **Where** can I turn for services? (4)
- VI. **What** does the future hold? (5)

IV. 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 issues I need to know about?

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

Treatment Initiative Ideas From Scientific Workshops

- Develop and evaluate treatments that improve functioning and quality of life for older children and adults with ASD
- Early interventions that prevent the development of ASD in very young at-risk children and reduce family burden
- Large scale studies that directly compare interventions and combinations of interventions in order to identify what works best for which individuals and how much it will cost
- Determining the optimal treatment of co-existing medical or psychiatric conditions and whether treatment of these conditions improve ASD symptoms

Treatment Initiative Ideas from Scientific Workshops

- Clinical trials that assess the safety and success of widely used biomedical treatments that have not been formally studied for the treatment of ASD
- Animal models and cellular studies that apply findings from genetic and biological research to targeted ASD treatments
- Funding or grant mechanisms that facilitate rapid translation of promising scientific discoveries into clinical trials
- Identification of biological differences that are associated with ASD subtypes and correlate to treatment response
- Development of innovative treatments that specifically target symptom clusters unique to ASD

Autism Town Hall Meeting: Goals and Products

Solicit public input on autism treatment research priorities for Strategic Plan

Summarize public comments

Present summary to IACC at May 12th meeting

Use summary to help inform further development and refinement of the Strategic Research Plan