

# IACC Strategic Plan for Autism Spectrum Disorder Research

IACC Strategic Plan Workgroup  
Conference Call  
December 12, 2007

# 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. (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)

# Meeting Accomplishments

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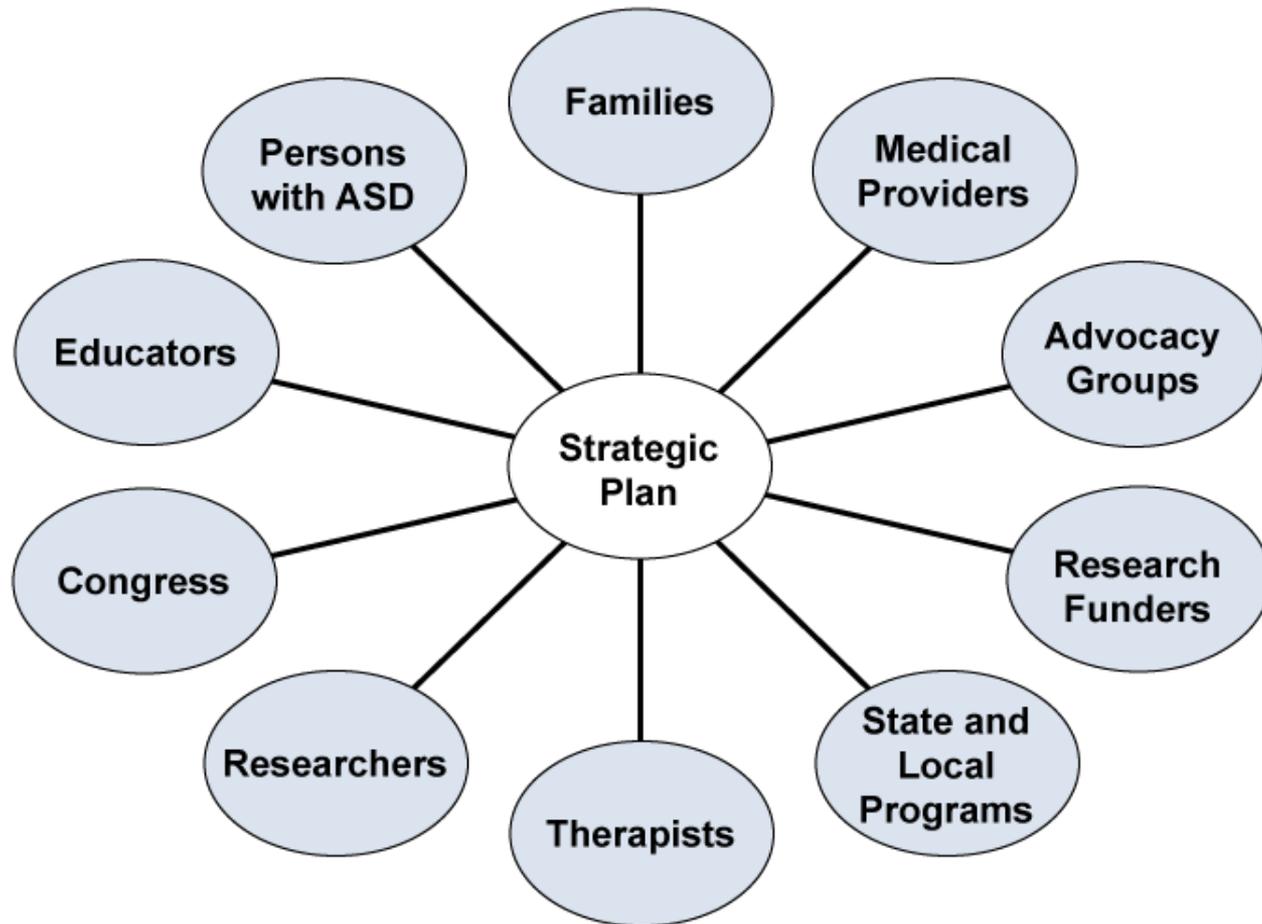
- Discussed and approved a process for developing the Strategic Plan (SP) for ASD Research
- Approved establishment of a SP workgroup

# Guiding Principles for the Process Plan

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- Stakeholder Involvement
- Government and Private Investment
- Responsiveness
- Priority-Setting

# Stakeholder Involvement



# Government and Private Investment

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- ASD research is characterized by government and non-governmental funding
  - Many researchers are funded by both types of funding sources
- Improved synergy across types of organizations is a goal of the SP

# Responsiveness

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- Incorporate and reflect urgency of public health importance of ASD
- Be informed by leading edge science and knowledge
- Insure flexibility and responsiveness through annual updates of SP
  - Think of the 2008 plan as Version 1.0

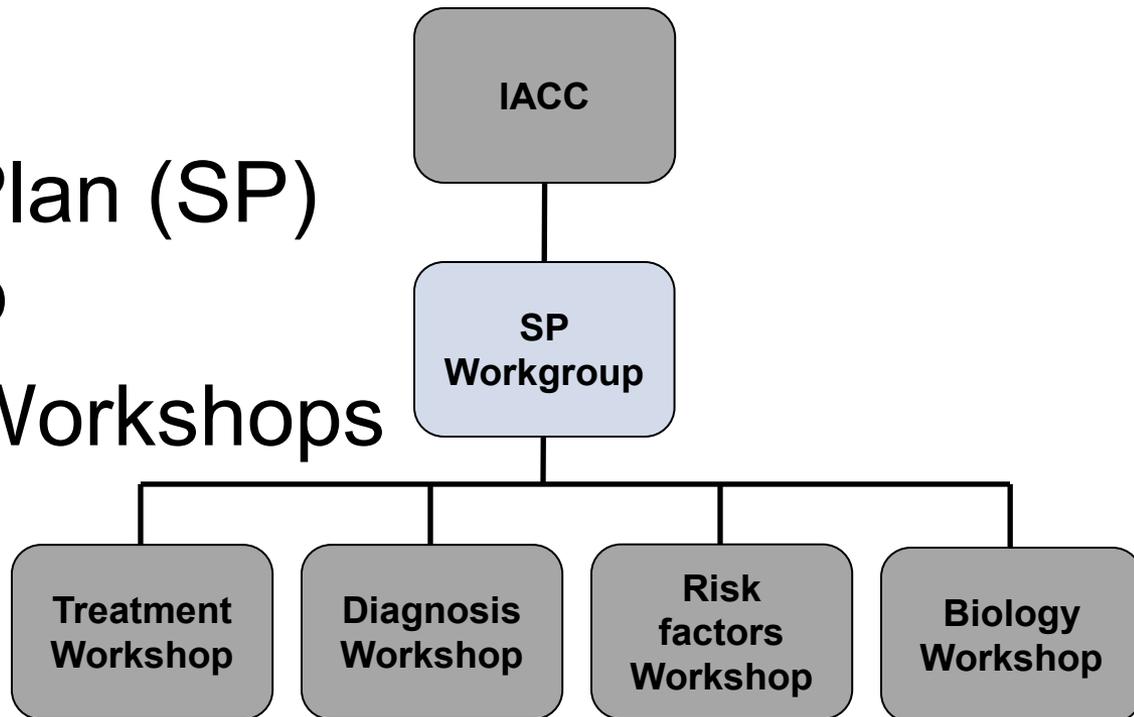
# Priority-Setting

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- The strategic plan will establish research priorities
- Priority-setting allows the research to be strategic and future-oriented
- Progress on priorities will be measurable
- Priorities will guide implementation

# Structure for Strategic Planning

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



All will involve

- Stakeholders
- NIMH Autism Team

# Structure for Strategic Planning

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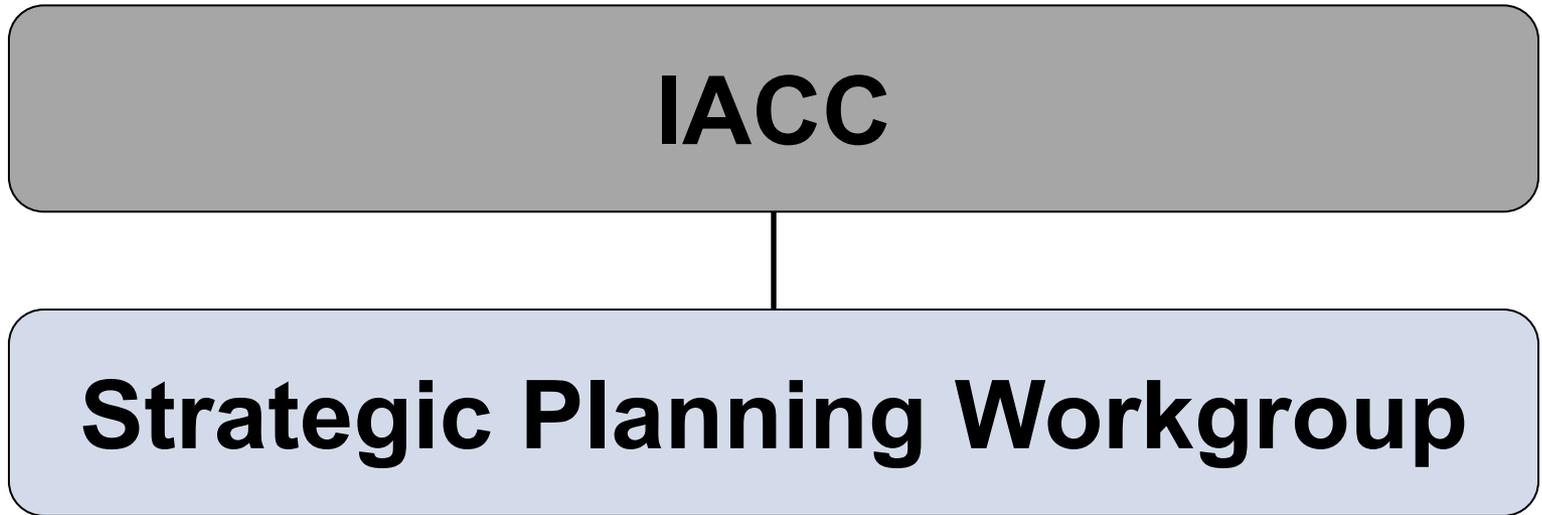


**IACC**

**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

# Structure for Strategic Planning

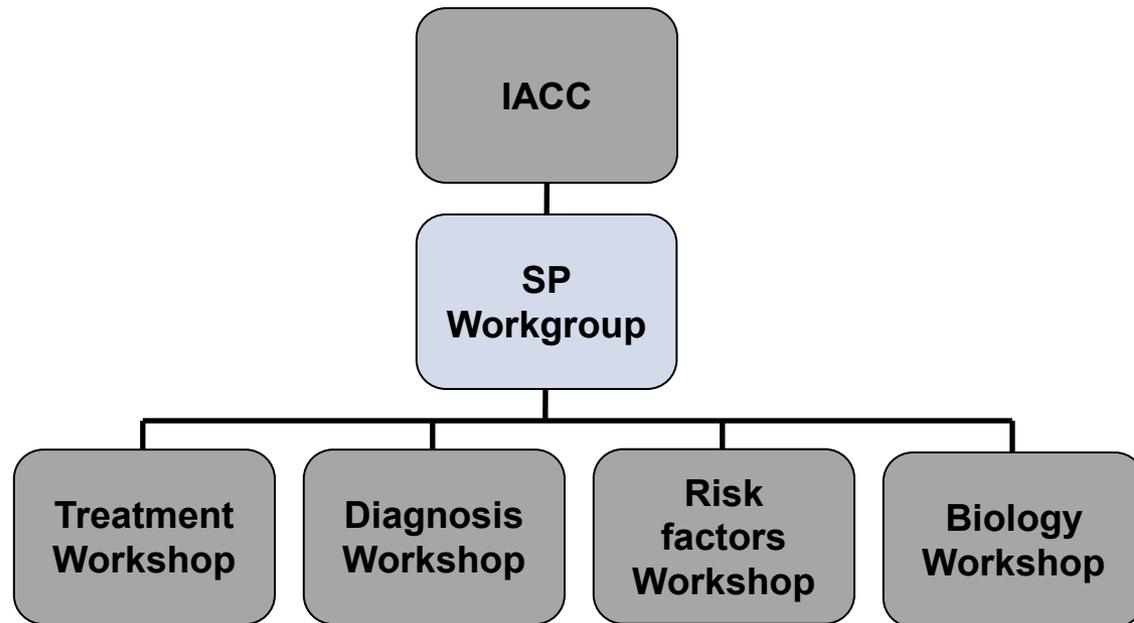
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**SP Workgroup** - established by the IACC to facilitate the development of the strategic plan; workgroup provides scientific expertise and includes representatives from government and private ASD research agencies and organizations and at least one IACC member.

# Structure for Strategic Planning

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**Scientific Workshops:** will be composed of IACC members, researchers, and other representatives. Each workshop will forward research priorities to the SP Workgroup to consolidate and forward to the IACC for consideration.

# Workshop Domains

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## Treatment

- 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.

# Workshop Domains

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## 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.

# Workshop Domains

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## 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 Domains

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## Biology

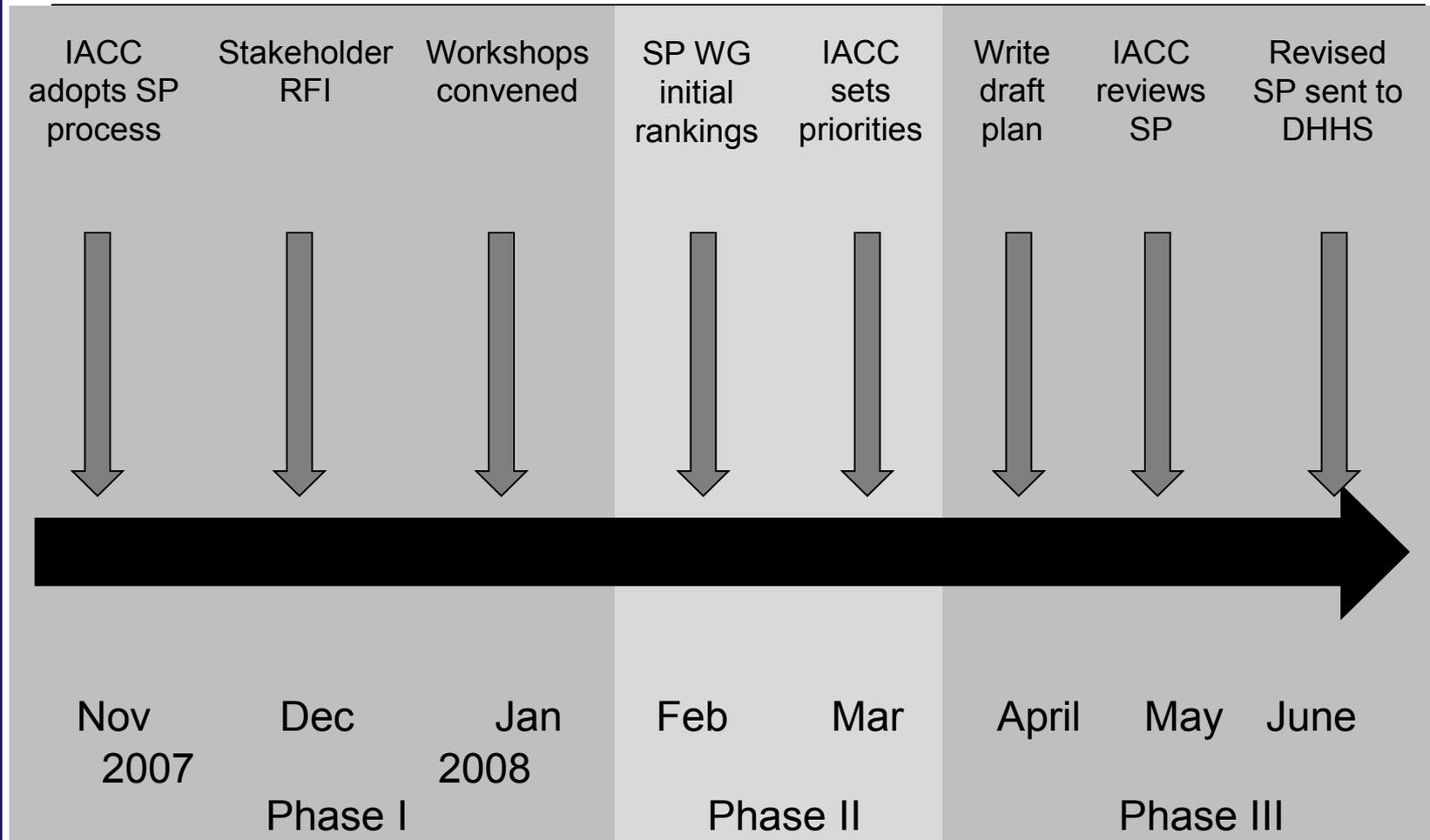
- The underlying biological processes that lead to developmental and medical problems associated with ASD.
- This includes research in the area of neurosciences but does not confine itself to neurosciences. Therefore, research on other organ systems, interactions between organ systems, and/or other disease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

# Strategic Planning Process

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- **Timeline of approximately six months** (November 2007 to May 2008)
- **Three phases:**
  - Develop of strategic priorities
  - Plan development and consolidation
  - Final document approval
- **Annual update**

# Timeline for Strategic Plan for ASD Research



# I. Development of Strategic Priorities

Process Phase	Approximate Timing
A. Brainstorming Meeting to Start Process	August 2007
B. Develop Draft Process Plan for Strategic Plan (SP)	September October
C. IACC Meeting: Discuss & Adopt Process Plan for SP	November
D. SP Workgroup: Organize SP Process and Participants	December
E. Stakeholder: RFI to Seek Input on Research Priorities	
F. Four Scientific Workshops to Generate Research Priorities	January 2008

**IACC**

**SP Workgroup**

**Stakeholders**

**Workgroups**

**NIMH Autism Team**

## II. Plan Development & Consolidation

Process Phase	Approximate Timing
G. SP Workgroup: Preliminary Ranking of Overall Priorities	February 2008
H. Stakeholder: Feedback on Preliminary Ranking of Priorities	
I. IACC Meeting: Finalize Priorities & Discuss Budgetary Requirements for SP	March
J. Begin to Write Strategic Plan	April

**IACC**

**SP Workgroup**

**Stakeholders**

**Workgroups**

**NIMH Autism Team**

## III. Final Document Approval

Process Phase		Approximate Timing		
K.	SP Workgroup: Consider Implementation Process for Top Research Priorities	April 2008		
L.	Distribute First Draft of Strategic Plan to IACC	May		
M.	IACC Meeting: Review Draft Strategic Plan & Discuss Implementation			
N.	Stakeholder: Comments on Final Plan	June		
O.	Revise Strategic Plan and Sent to DHHS			
P.	Form Implementation Workgroup			
<b>IACC</b>	<b>SP Workgroup</b>	<b>Stakeholders</b>	<b>Workgroups</b>	<b>NIMH Autism Team</b>

# Annual Update of Strategic Plan

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- Identify progress on SP priorities
- Stakeholder input on SP priority progress
- Revise and update SP as needed