

# IACC Strategic Plan for Autism Spectrum Disorder Research

NIMH Autism Team  
November 30, 2007



# Today's Goals

- Discuss and adopt a process for developing the Strategic Plan (SP) for ASD Research
- Approve establishment of a SP workgroup

# Brainstorming Meeting

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- **Purpose:** meeting to gather individual ideas, not reach consensus
- **Organizer:** Thomas Insel, NIMH
- **Participants:**
  - Insel (NIMH)
  - Bell (Autism Speaks)
  - Fischbach (Simons Found.)
  - Redwood (SafeMinds)
  - Wagner (NIH-ACC)
  - Piven (UNC)
  - Trevathan (CDC)
  - Resnick (SARRC)
- **Date:** August 2007 (after NIMH was delegated management of the IACC)

# Brainstorming Meeting

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- Although opinions varied on scope and organization of SP, the main ideas were the following:
  - Stakeholder involvement is critical
  - Need to encompass government and private ASD funding organizations
  - Need to include research cost estimates
  - Very helpful if NIMH would develop a draft process for the SP prior to the IACC meeting

# Guiding Principles for Development of Process Plan

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

# Stakeholders



For Discussion Only, Does Not Represent Decisions of the IACC.

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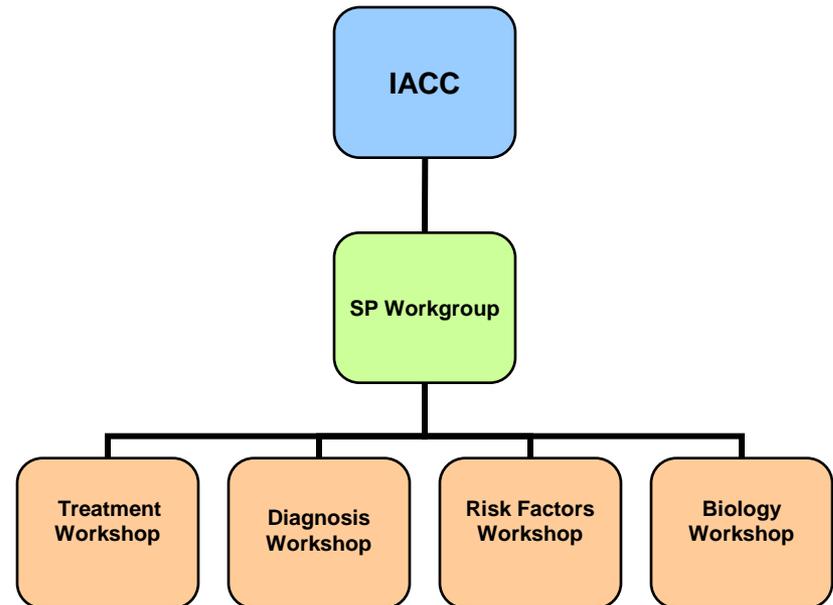
- Incorporate and reflect urgency of public health importance of ASD
- Be informed by leading edge science and knowledge
- Insure flexibility and responsiveness through annual updates of SP
  - Think of the 2008 plan as Version 1.0

# Priority-Setting

- 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

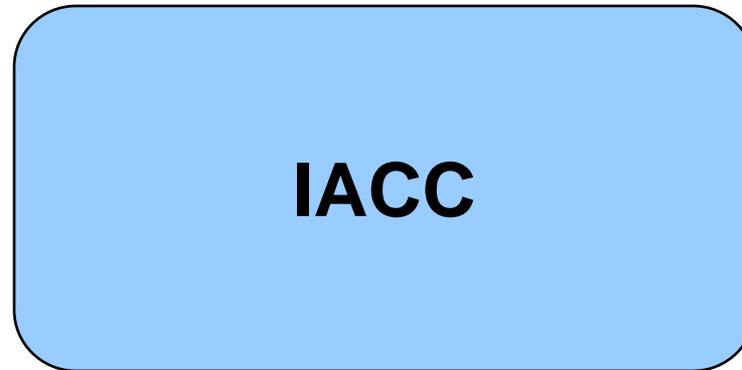
# Proposed Structure for Strategic Planning

- IACC
- Strategic Plan (SP) Workgroup
- Scientific Workshops
  - All will involve
    - Stakeholders
    - NIMH Autism Team



# Proposed Structure for Strategic Planning

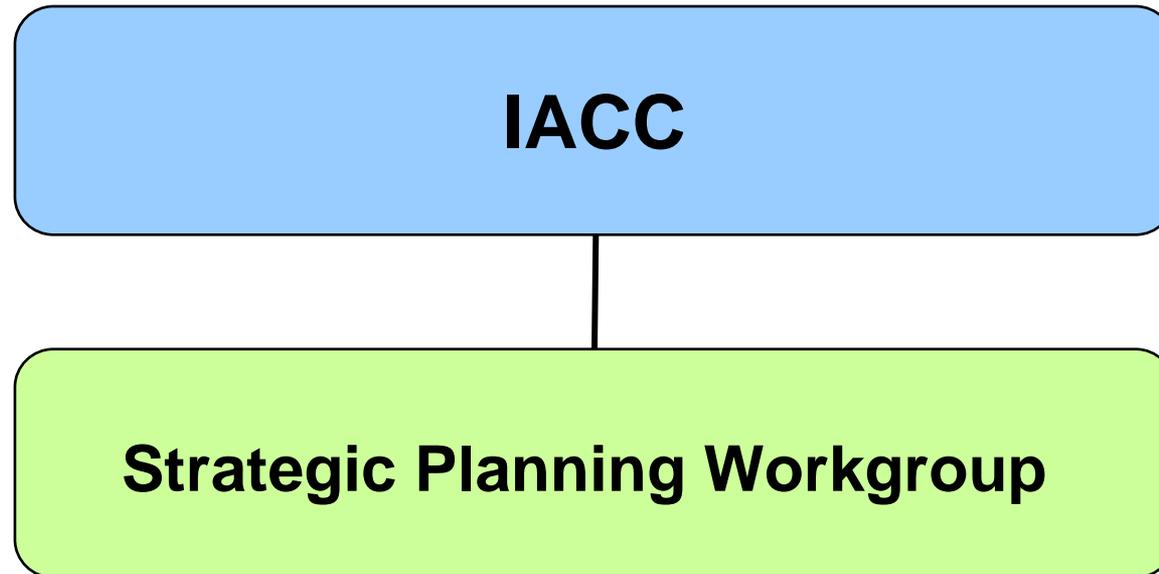
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**IACC** – the parent body established by the Combating Autism Act of 2006 (CAA), mandated by CAA to develop and annually update a strategic plan for the conduct of and support for ASD research

# Proposed Structure for Strategic Planning

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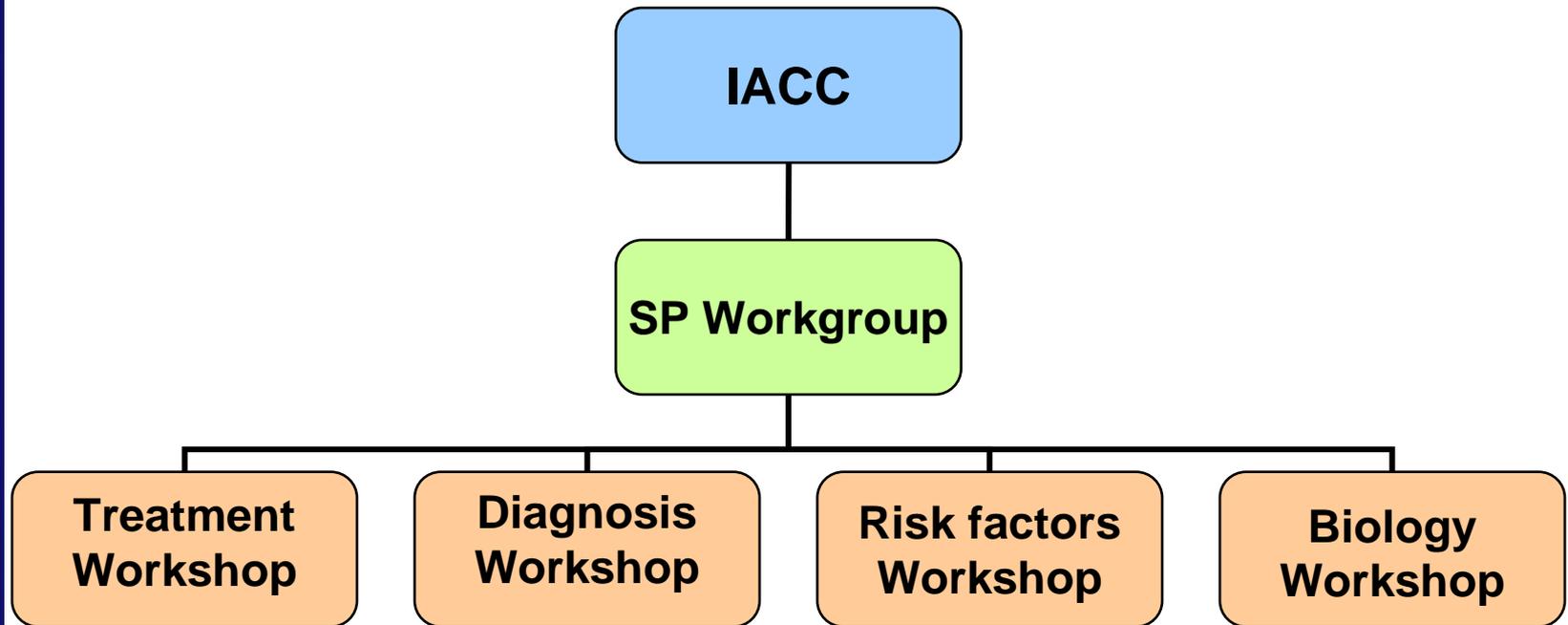


**SP Workgroup** – established by the IACC to facilitate the development of the strategic plan; workgroup provides scientific expertise and includes representatives from government and private ASD research agencies and organizations and at least one IACC member.

# Proposed SP Workgroup Composition

- Provides additional expertise for the IACC
- Representatives from major government and private funding organizations
- Scientific workshop chairs
- Other contributing members: At least one IACC member required
- IACC Chair will appoint SP Workgroup members

# Proposed Structure for Strategic Planning



**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

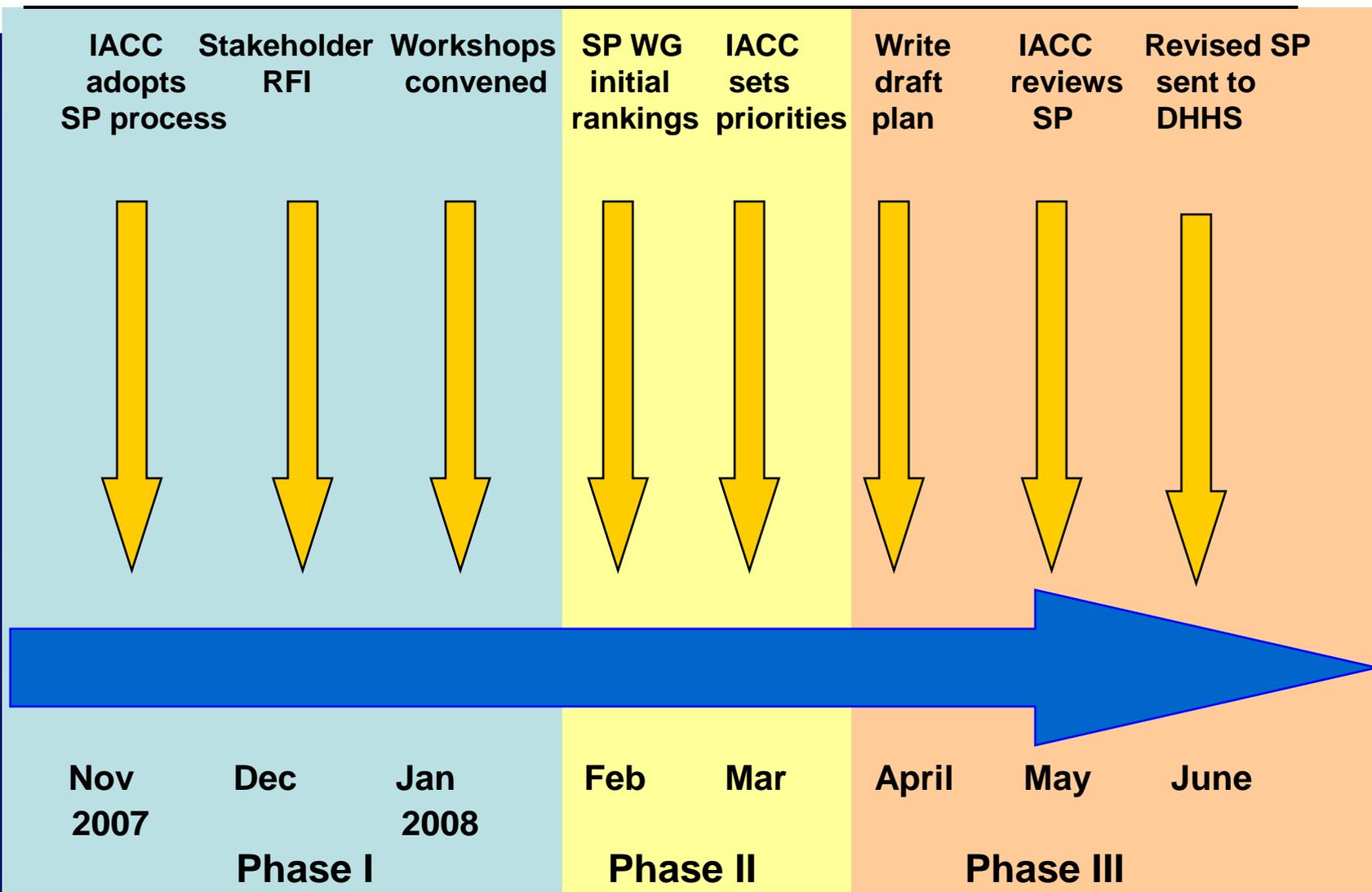
- **Treatment:** how to improve the outcomes for individuals with ASD
- **Diagnosis:** how to best describe and identify ASD
- **Risk Factors:** which genetic and/or environmental factors influence the occurrence of ASD
- **Biology:** what underlying processes lead to developmental & medical problems in ASD

# Proposed 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



For Discussion Only, Does Not Represent Decisions of the IACC.

# 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

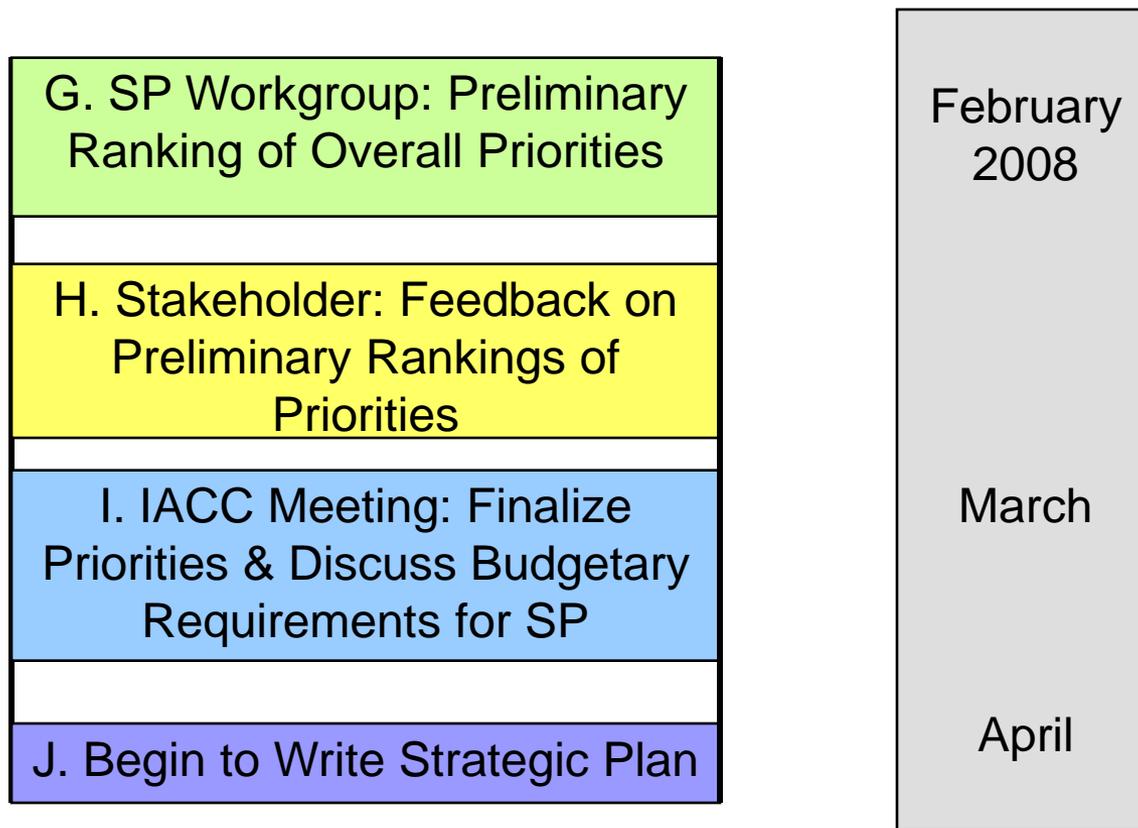
Workshops

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# II. Plan Development & Consolidation

## Process Phase

## Approximate Timing



IACC

SP Workgroup

Stakeholders

Workshops

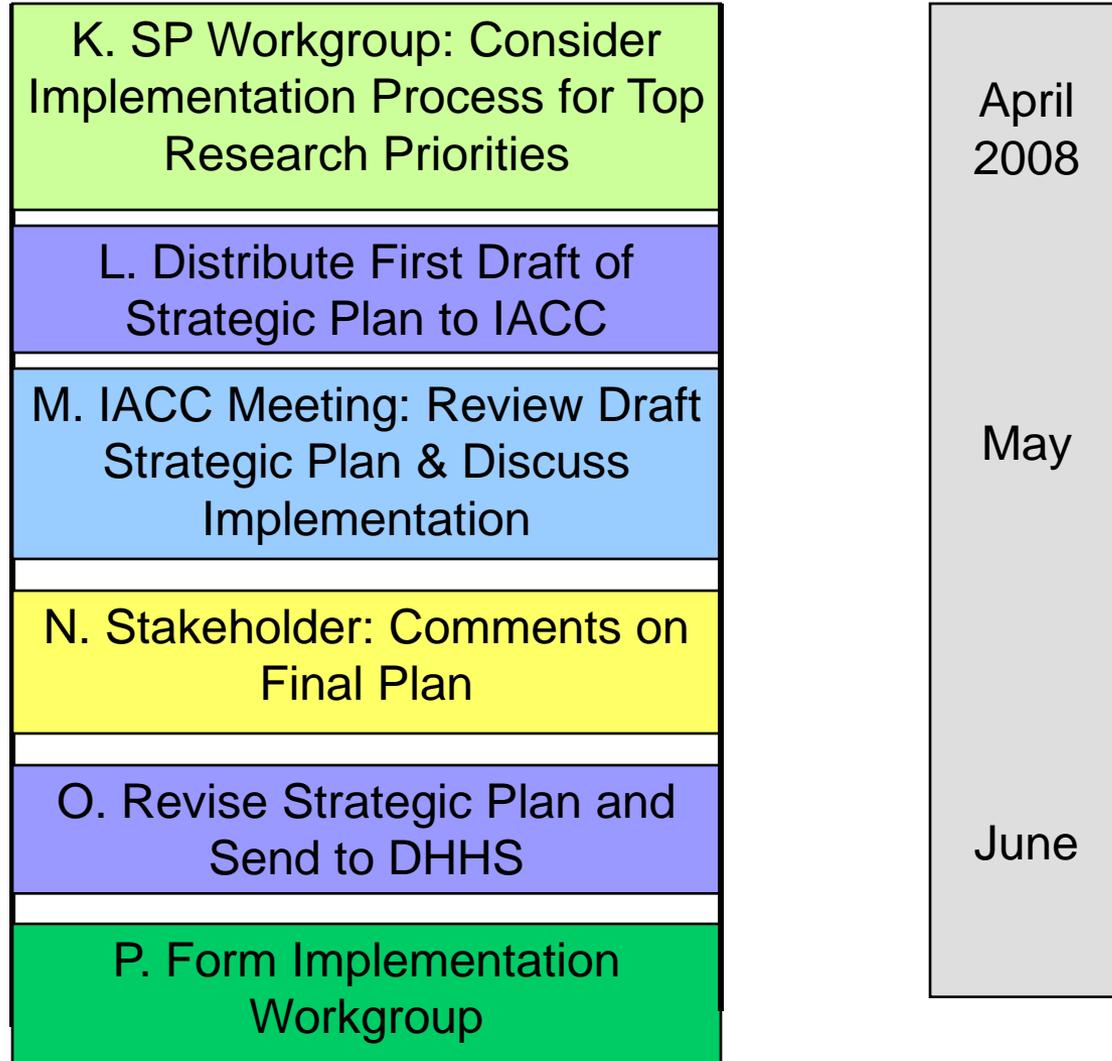
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# III. Final Document Approval

## Process Phase

## Approximate Timing



# 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



# Decisions for IACC

- Discussion and adoption of a process for developing the SP for ASD Research
- Approve establishment of a SP Workgroup

