

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

- **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)

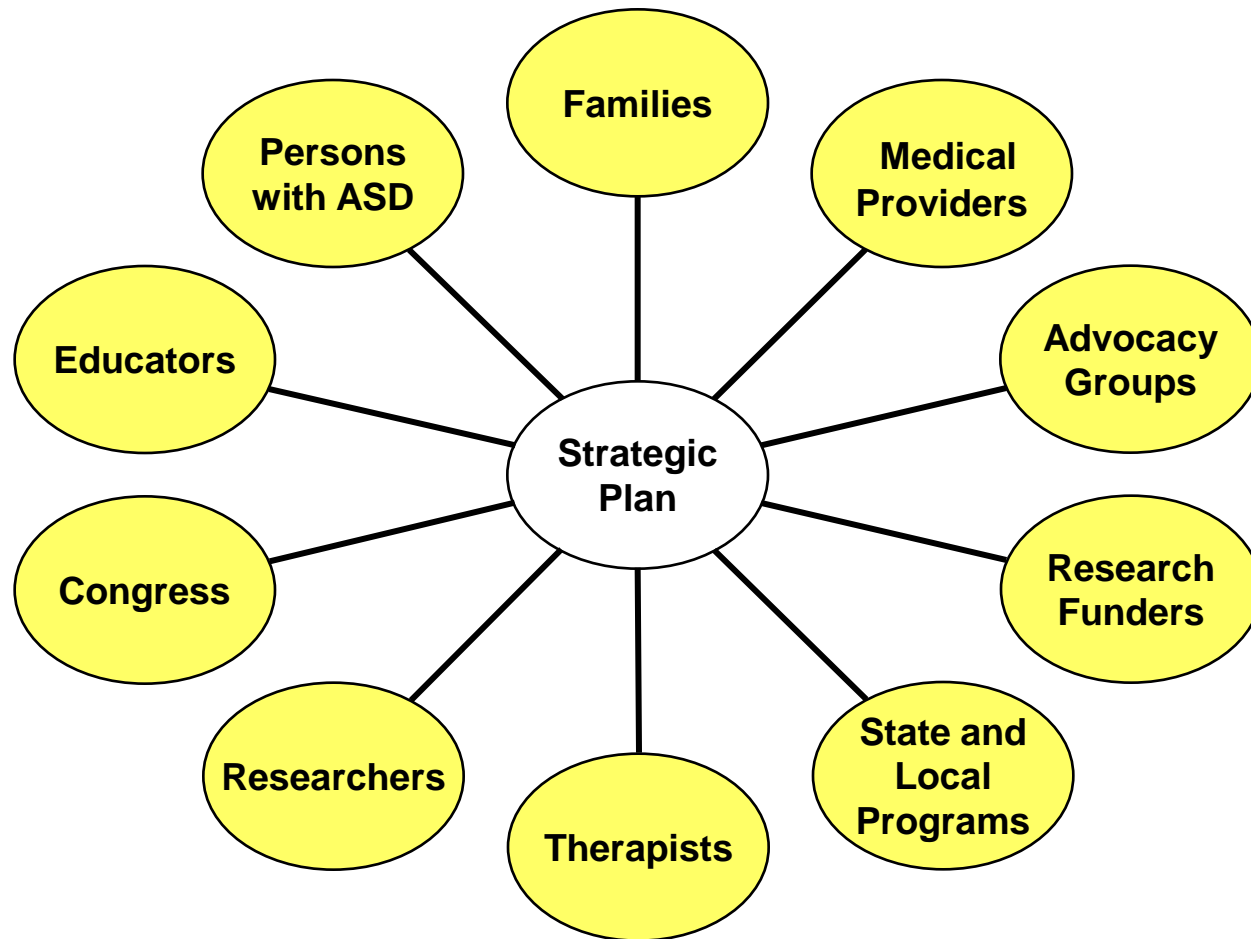
Brainstorming Meeting

- 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

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

Stakeholders



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

Government and Private Investment

- 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

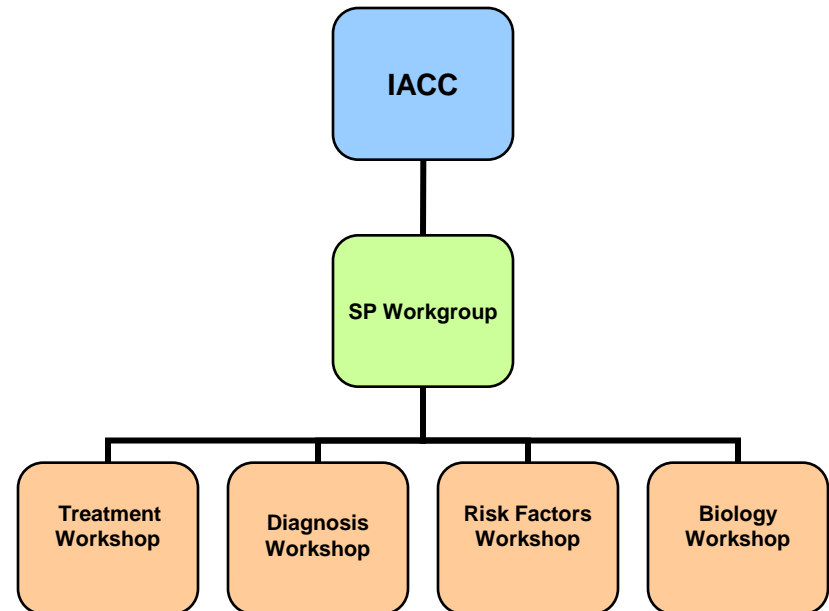
- Incorporate and reflect urgency of public health importance of ASD
- Be informed by leading edge science and knowledge
- Insure flexibility and responsiveness through annual updates of SP
 - Think of the 2008 plan as Version 1.0

Priority-Setting

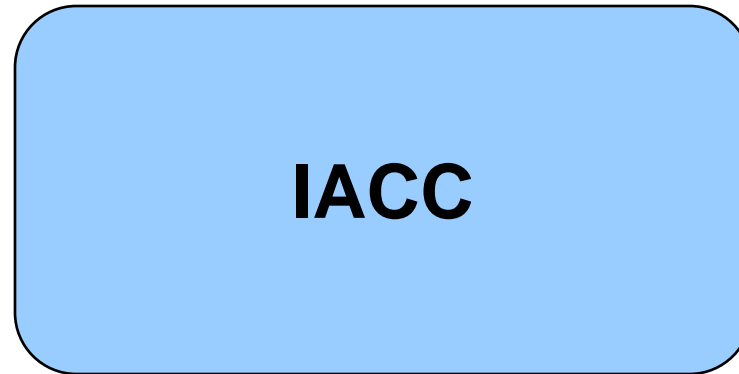
- The strategic plan will establish research priorities
- Priority-setting allows the research to be strategic and future-oriented
- Progress on priorities will be measurable
- Priorities will guide implementation

Proposed Structure for Strategic Planning

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

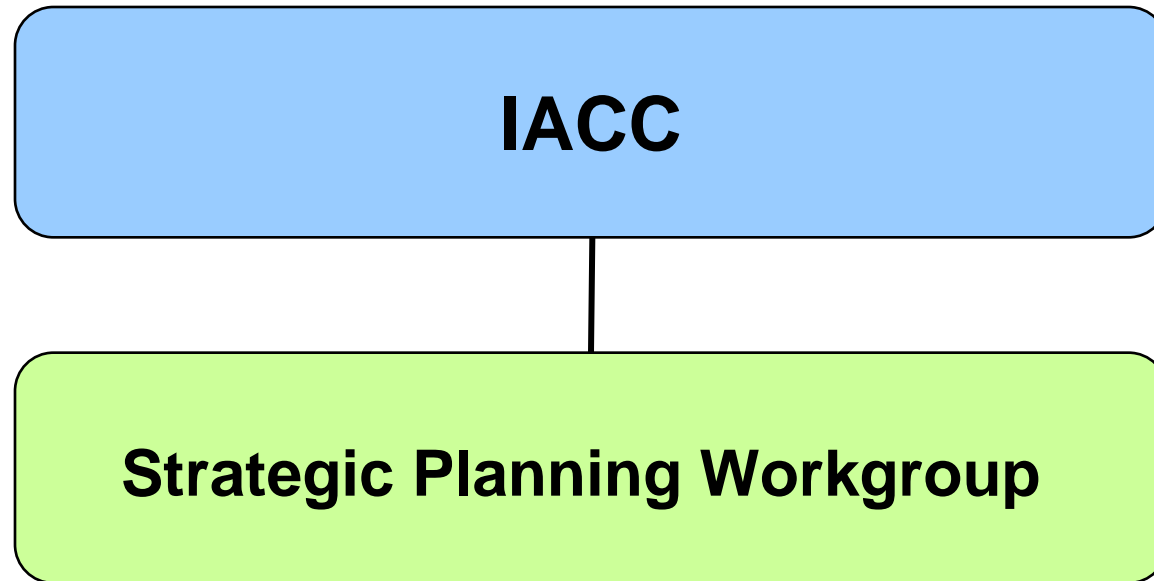


Proposed Structure for Strategic Planning



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

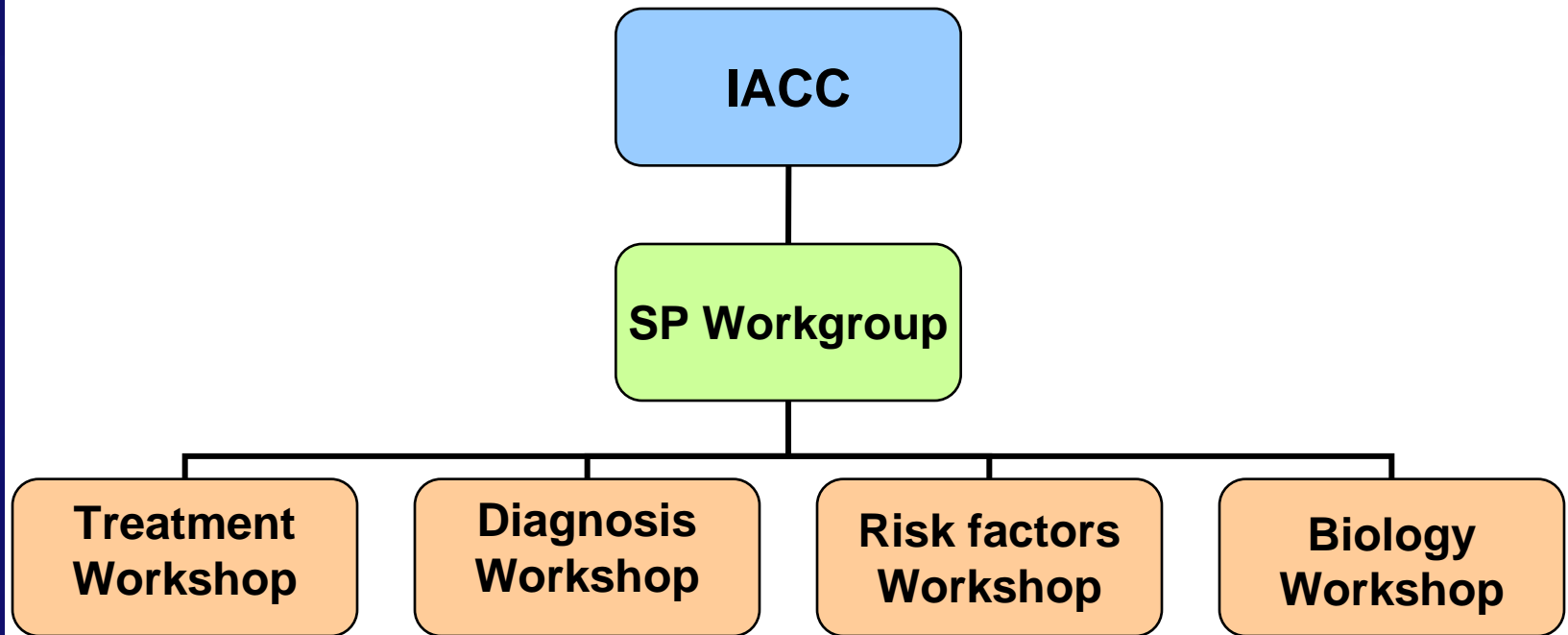


SP Workgroup – established by the IACC to facilitate the development of the strategic plan; workgroup provides scientific expertise and includes representatives from government and private ASD research agencies and organizations and at least one IACC member.

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.

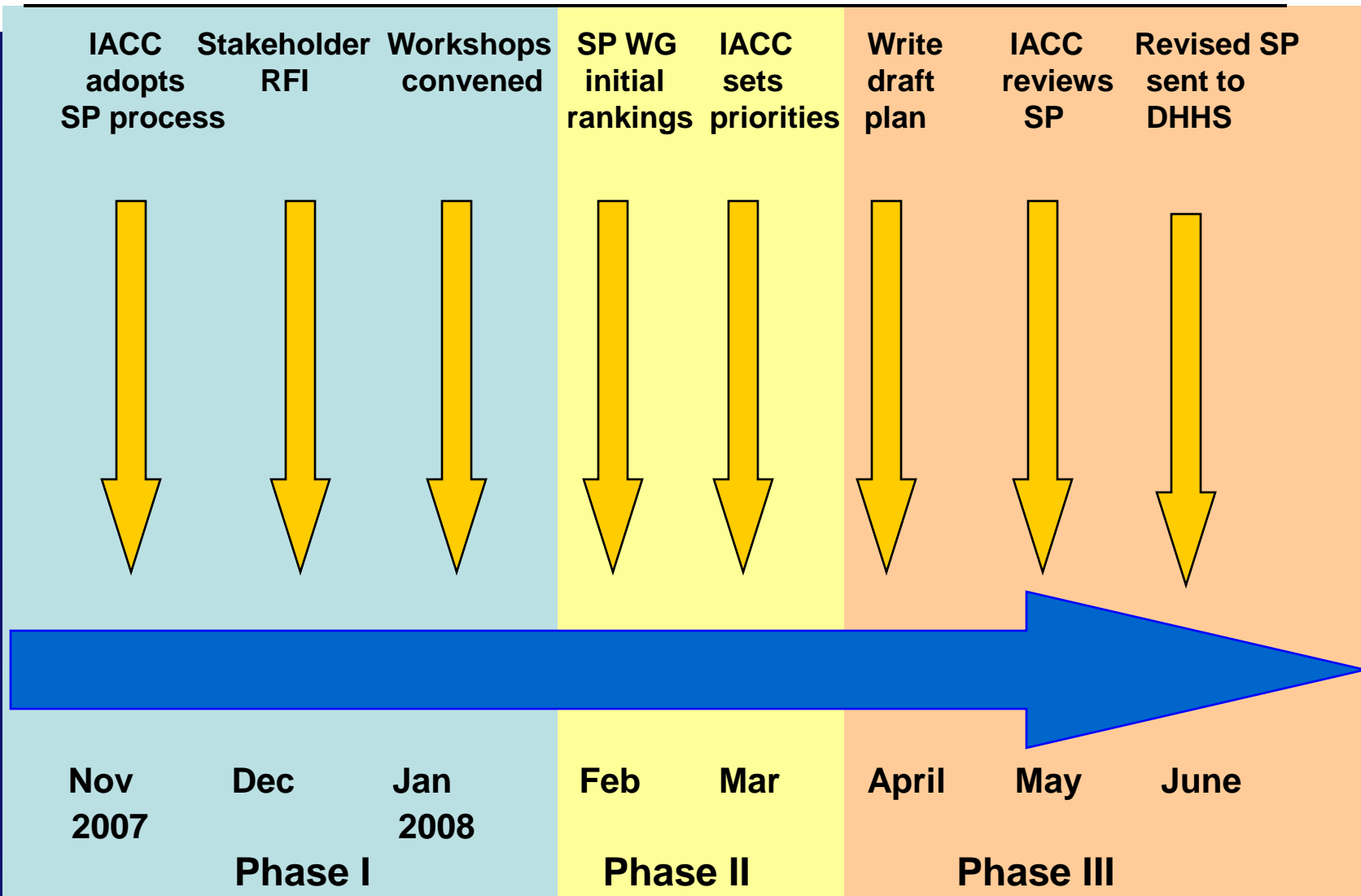
Workshop Domains

- **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

- **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



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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

NIMH Autism Team

II. Plan Development & Consolidation

Process Phase

Approximate Timing

G. SP Workgroup: Preliminary Ranking of Overall Priorities
H. Stakeholder: Feedback on Preliminary Rankings of Priorities
I. IACC Meeting: Finalize Priorities & Discuss Budgetary Requirements for SP
J. Begin to Write Strategic Plan

February
2008

March

April

IACC

SP Workgroup

Stakeholders

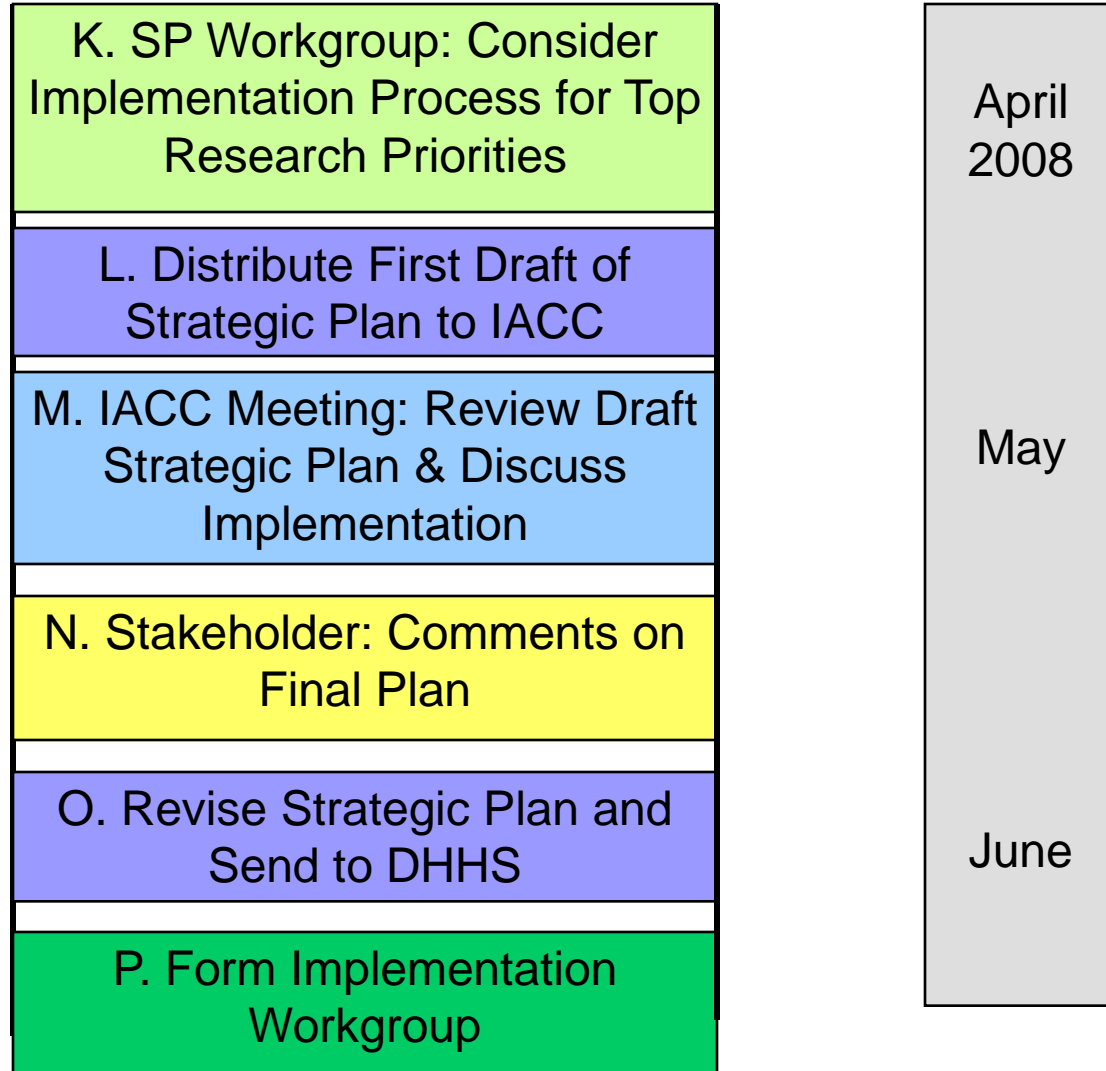
Workshops

NIMH Autism Team

III. Final Document Approval

Process Phase

Approximate Timing



Annual Update of Strategic Plan

- 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

