

Meeting of the IACC

OARC/IACC Update

Susan A. Daniels, Ph.D.

Director, Office of Autism Research Coordination, NIMH
and Executive Secretary, IACC

Thomas Insel, M.D.

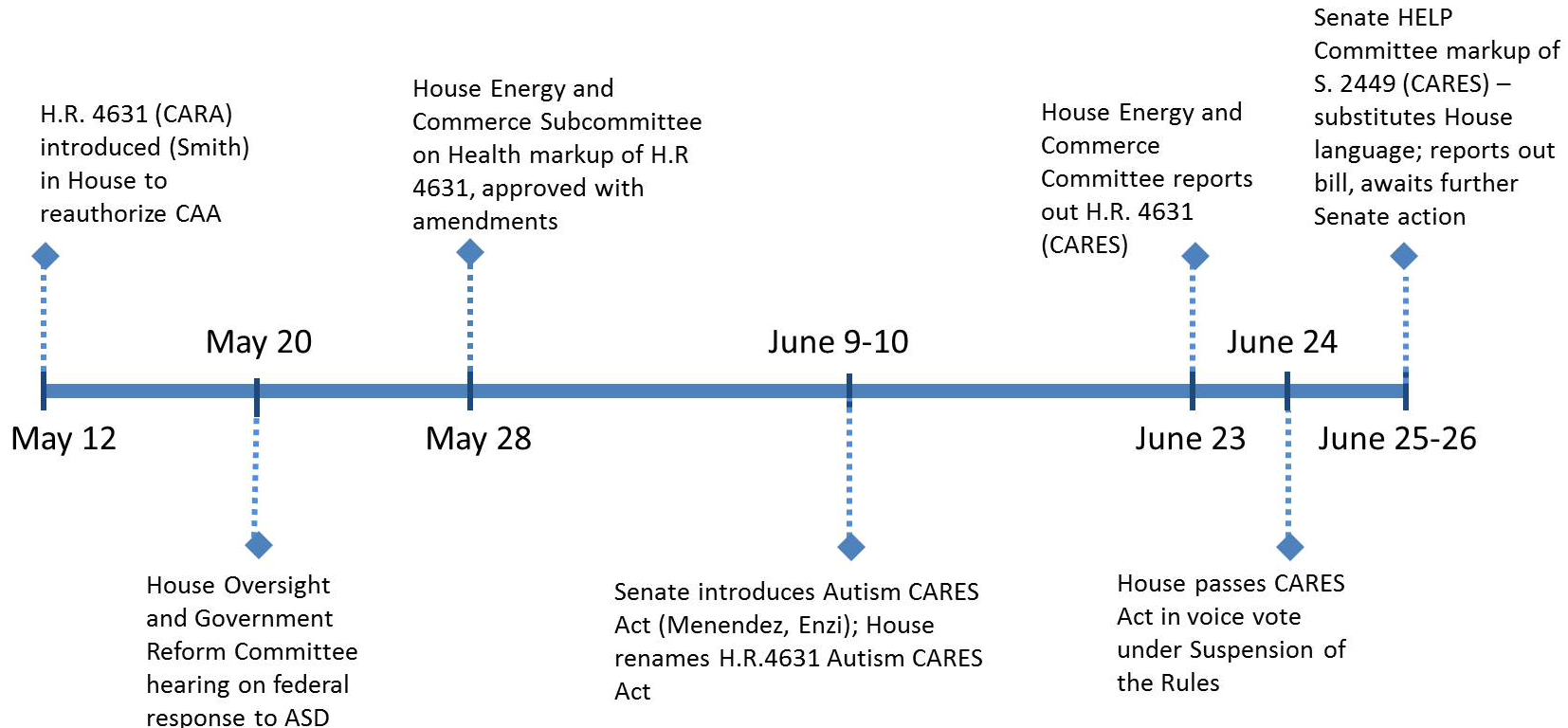
Director, NIMH and Chair, IACC

What is Next for the IACC?

The Combating Autism Reauthorization Act (CARA) of 2011 (P.L. 112-32) expires on September 3, 2014

- Without a new reauthorization, the IACC is scheduled to sunset on September 30, 2014
- Current IACC member terms expire on September 30, 2014
- If there is a reauthorization before September 30, 2014, the committee will not sunset (i.e., cease to exist), but current member terms will expire
- The next steps will depend on the provisions of the reauthorization
- If reauthorized, the IACC will be re-formed under the new law, with an open call for nominations from the public for new potential public members
- Members will be selected by the official authorized to make the appointments (the HHS Secretary, or any other person designated in the law)

Autism CARES Legislation Timeline



Autism CARES Legislation

H.R. 4631, S. 2449: The Autism Collaboration, Accountability, Research, Education and Support Act would:

- Reauthorize the IACC and other programs through 2019
- Establish a National Autism Spectrum Disorder Initiative within HHS, led by an official charged with implementation of autism activities and ensuring that HHS activities are not unnecessarily duplicative of other federal Department and agency activities
- Incorporate a greater emphasis on services into various activities of the IACC (e.g., Strategic Plan)
- Provide further specification for membership
- Incorporate a significant emphasis on adults and transitioning youth services into the Report to Congress

World Health Assembly Resolution



Comprehensive and coordinated efforts for the management of autism spectrum disorders

May 24, 2014

- Co-sponsored by over 50 countries and supported by all 194 member states of the WHO
- Briefly describes ASD and key issues for those on the autism spectrum, including healthcare and human rights
- Identifies key challenges and priorities for ASD policy in member states, including healthcare and service provision, and protection of human rights
- Requests the WHO Director-General to engage with and support member states in strengthening their recognition and support for people on the autism spectrum
- Establishes ASD as a global health priority

World Health Assembly Resolution

Executive Board



World Health Assembly



- Work on a report and resolution on ASD began in 2013, led by Bangladesh, with significant contribution from nations including Qatar, India, Albania, and Panama
- The WHA Executive Board (the WHO advisory body composed of 34 elected experts) adopted the resolution In May 2013
- In May 2014, the full WHA, composed of health ministers from around the world, adopted a revised resolution
- The resolution represents a formal commitment from all 194 member states

World Health Assembly Resolution

Member State Priorities:

- Develop and update national ASD policies, strategies, programs, and laws, as a part of multisectoral and comprehensive plans to address mental health conditions and developmental disabilities
- Increase healthcare and social service capacity and infrastructure, focusing on community-based services
- Support research, data gathering/surveillance efforts, awareness campaigns and efforts to protect human rights and dignity
- Increase family support, integration of adults with ASD
- Reduce disparities and strengthen international collaboration

World Health Assembly Resolution

Requests to Director-General:

- Work with member states to support implementation efforts and collaboration
- Facilitate resource mobilization for challenged areas
- Implement changes to scale-up care for those with ASD
- Monitor and report on progress

Co-occurring Conditions Workshop

Tuesday, September 23, 2014
Porter Neuroscience Center, NIH

Focus on under-recognized co-occurring health conditions in children and adults with ASD and how the IACC can support research and community/provider awareness, and foster development of clinical practice guidelines in areas where they are needed.

Panel 1	Overview of co-occurring conditions in children and adults with ASD
Panel 2	Psychiatric disorders
Panel 3	Sleep and neurological disorders
Panel 4	Metabolic and immune disorders