Subcommittee for Services Research and Policy

Conference Call and Webinar

September 19, 2012

Conference Call Access:

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Subcommittee for Services Research and Policy

Agenda

10:00 AM   **Roll Call and Opening Remarks**

David Mandell, Sc.D., Co-Chair

Associate Professor, Dept. of Psychiatry and Pediatrics
University of Pennsylvania

Denise Dougherty, Ph.D., Co-Chair

Senior Advisor, Child Health and Quality Improvement
Agency for Healthcare Research and Quality (AHRQ)

10:15   **Overview and Discussion of Process to Update the Strategic Plan**

- **Review Subcommittee Charge**
- **Discuss Topic Areas**

11:00   **Workshop Planning**

- **Determine Slate of External Experts**
- **Assign Subcommittee Members to Topic Areas**
- **Discuss Draft Template for Updates**
- **Establish Workshop Schedule**

2:00 PM   **Adjournment**

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Subcommittee for Services Research and Policy

Overview and Discussion of Process to Update the Strategic Plan

Subcommittee Charge Statement

The Services Research and Policy Subcommittee of the Interagency Autism Coordinating Committee (IACC) will assist the IACC with its responsibility to provide advice to the Secretary of HHS on changing needs related to research and policy about the organization, financing and delivery of services for individuals with autism. These services include but are not limited to those that address identification and treatment needs, housing, employment, safety, and social inclusion. The Subcommittee's immediate task will be the update of the Research Strategic Plan. By Dec 1, 2012, the Subcommittee will provide to the full IACC a draft update of the sections entitled "What do we know?" and "What do we need to know?" for Chapters 5 and 6 of the 2011 version of the Plan. For the purposes of the Research Strategic Plan, the subcommittee will address what is known and needed in the area of services research. In addition to this initial task, this subcommittee will support IACC roles and responsibilities related to services research and policy, including assistance with the annual update of the Research Strategic Plan beyond 2012.

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Strategic Plan Update Process

- To facilitate the Update process, the subject matter of Questions 5 and 6 will be divided into broad topic areas

- In each topic area, external experts will work with a subcommittee member to produce a draft Update to share at the Workshop

  - Updates due to subcommittee co-chairs by October 15

- During the workshop, break-out groups will discuss the drafts and then report back to the full group with feedback and recommendations

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Deliverables

- Bulleted draft due to subcommittee co-chairs by Monday, October 15th

- Updates due to OARC by Monday, October 22nd

- Present and discuss Updates at Strategic Planning Workshop on October 29th

- Incorporate feedback and finalize Updates for the 2012 Strategic Plan for ASD Research to be submitted to Congress by December 2012

Strategic Plan Update Process

- For each topic, address the questions "What do we know?" and "What do we need?"

  – Focus on the past 18 months (since the release of the 2011 Strategic Plan in January 2011)

  – Include funded and unfunded gaps

  – Use the 2010 IACC Portfolio Analysis Report and the 2011 Summary of Advances in ASD Research to help answer these questions

  – Approximately 2-4 pages total for each Update

Topic Areas

- Access and coverage
  - Including transition to adulthood

- Quality of care
  - Coordination of care
  - Implementation

- Education / Workforce

- Family support

- Comparative effectiveness and patient centered outcomes research

All experts will be asked to address these topic areas as they relate to both children and adults. Each expert will also address the knowledge gained and remaining research needs regarding racial, ethnic, socio-economic and geographic/residence disparities within each topic area.

Subcommittee for Services Research and Policy

Workshop Planning

Access and Coverage

Suggested External Experts

- **Access and Coverage**
    - **Lorri Unumb, Esq.** (Autism Speaks)
    - **William Courtland Johnson, Ph.D.** (Center for Healthcare Strategies)
    - **Mark Schaefer** (State Medicaid Director - Connecticut)
    - **Christine Hunter, M.D.** (Office of Personnel Management)
    - Representative from **Aetna** or **OptumHealth** (private insurance coverage)
    - Representative from Pennsylvania (regarding the Pennsylvania adult autism waiver)

- **Transition**
    - **Paul Shattuck, Ph.D.** (Washington University in St. Louis)
    - **Susan Parish, Ph.D.**, MSW (Brandeis University)
    - **Megan Farley, Ph.D.** (University of Utah)
    - **Julie Taylor, Ph.D.** (Vanderbilt University)
    - **Leslie Long** (Autism Speaks, Director of Housing & Adult Services)

- **Group leader (IACC Member)**
    - TBD

Quality of Care

Suggested External Experts

- **Quality/Implementation of Evidence-Based Practice**
- **Coordination and Patient Navigation**

  - **Aubyn Stahmer, Ph.D.** (University of California, San Diego)
  - **Donna Noyes, Ph.D.** (Associate Director for Clinical Policy for the Bureau of Early Intervention, New York State Department of Health)
  - **James Perrin, M.D.** (Harvard Medical School; Director of the Clinical Coordinating Center for the Autism Treatment Network)
  - **Connie Kasari, Ph.D.** (University of California, Los Angeles)

Group leader (IACC Member)

  - TBD

Education / Workforce

Suggested External Experts

- **Philip Strain, Ph.D.** (University of Colorado at Denver)
- **Sam Odom, Ph.D.** (University of North Carolina at Chapel Hill)
- **Colleen Weick, Ph.D.** (Executive Director of the Minnesota Governor's Council on Disabilities)
- **Amy Wetherby, Ph.D.** (Florida State University)
- **Peter Gerhardt, Ph.D.** (Director of Education – Upper School, McCarton School in New York City)
- **Cathy Pratt, Ph.D., BCBA-D** (Director of the Indiana Resource Center for Autism at the Indiana Institute on Disability and Community located at Indiana University)
- **David Hagner, Ph.D.** (University of New Hampshire)
- **Valerie Paradiz, Ph.D.** (designs curricula and educational programs for children and adults with ASD)

Group leader (IACC Member)

- TBD

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Family Support

Suggested External Experts

- **Ann Turnbull, Ed.D.** (University of Kansas)
- **Mark Woodsmall, Esq.** (trust planning for special needs; special education)
- **Temple Grandin, Ph.D.**
- **Eustacia Cutler** (Temple Grandin's mother)

Group leader (IACC Member)

- TBD

Comparative Effectiveness and Patient-Centered Outcomes Research

Suggested External Experts

- **Anne Beal, M.D., M.P.H.** (Patient-Centered Outcomes Research Institute – PCORI)
- **Lisa Simpson, M.B., BCh, MPH** (President and CEO, AcademyHealth)
- **Lisa Prosser, Ph.D.** (University of Michigan)
- **Kathleen Thomas, Ph.D.** (University of North Carolina at Chapel Hill)

Group leader (IACC Member)

- TBD

Template for Updates

Use the "2011 Addendum" sections of the 2011 Strategic Plan as a guide

- Also reference the "What do we know?" and "What do we need to know?" sections to ensure that all topics are covered
- Pages 47-50 and 54-57 in the pdf document

For each question, address (in general):

- What are new key findings or discoveries from the past 18 months, and why are they important?
- What have we learned from the 2011 Summary of Advances and the 2010 Portfolio Analysis?
- Newly funded research that addresses gap areas
- What gap areas remain and how might they be addressed?
- What are the needs of the community?

Timeline

Date	Task/Responsibility
Beginning 9/19	Invite Experts (OARC)
Week of 9/24	Contact Experts to Begin Work on Assigned Topic Area (Assigned IACC Member)
10/15/2012	Submit Update (2-4 pages per Topic) to Subcommittee Co-Chairs
10/22/2012	Subcommittee Co-Chairs submit near-final draft update to OARC for distribution to 10/29 meeting attendees
10/29/2012	IACC SRP Workshop – complete next draft of update
11/15/2012	Co-chairs submit near-final updates (Ch. 5, Ch. 6) to SRP Subcommittee for review
11/21/2012	Subcommittee comments due to co-chairs
Late November	SRP subcommittee conference call to approve Strategic Plan Update for Ch. 5 & 6
December	IACC full committee meeting to approve all Strategic Plan Updates
12/31/2012	Strategic Plan submitted to Congress

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Services Research and Policy Strategic Planning Workshop

October 29, 2012
Draft Agenda

- Opening: Introductions, Purpose
- Breakout Groups by Topic
- Report Back (Plenary)
- Revise
- Adjourn

Subcommittee for Services Research and Policy

Adjournment