Conference Call for IACC Scientific Workshop Panel Five
Strategic Plan Questions V & VI: *"Where Can I Turn for Services?"* and *"What Does the Future Hold?"*
Monday, September 14, 2009

Call Participants: Ellen Blackwell (Co-Chair), Christine McKee (Co-Chair); Panelists: Tec Chapman, Peter Gerhardt, Ann Gibbons, David Mandell, Cathy Pratt, and Marjorie Solomon; Susan Daniels (OARC Staff)

Summary:

The panelists introduced themselves and Ms. Ellen Blackwell, co-chair, began by reviewing Question V in the current version of the IACC Strategic Plan for ASD Research. Ms. Christine McKee said that she hoped to expand the services content of the Strategic Plan because it was underrepresented. Dr. Daniels told the panelists that they would receive information about the autism grants funded under the American Recovery and Reinvestment Act (ARRA) at the opening session of the Scientific Workshop.

The panelists discussed the "Research Opportunities" section of the Plan; Ms. Blackwell reported that the "State of the States" review being conducted by CMS would fulfill the first short-term objective. The panelists discussed the importance of applying research to the real-world setting, and recommended developing and testing interventions in partnership with the communities where they would be used. The panelists also noted that there were often discrepancies between what interventions practitioners report using and their actual practice. The panelists discussed the staggering amount of time it took to put research findings into practice, noting issues with dissemination and implementation.

The panel talked about how interventions (Question IV) related to services (Question V). Are services a subset of interventions? A vehicle for interventions? They also discussed whether they should specifically prescribe which interventions should be researched, to include promising practices being used in communities which may be overlooked. In addition, the panel discussed quality of life measures, access to care, and the importance of communicating results of treatment research to the public in understandable language.

Reviewing the Question V "Research Opportunities," Dr. David Mandell recommended re-framing the opportunities in terms of potential experiments. The panelists agreed that evidence-based practices had to be developed before they could be implemented, as called for in the "Effective dissemination of evidence-based practices for people with ASD at the community level."

After reviewing the Question V research objectives, the panelists agreed to recommend striking the second short-term objective and change the term "efficacy" to "effectiveness" in the first long-term objective. The panelists discussed a possible objective calling for better partnership between state and federal entities providing services and another dealing specifically with adults on the spectrum. Everyone was asked to brainstorm additional objectives and/or propose changes to existing language, to share during the next conference call.

The panelists briefly discussed Question VI, discussing the meaning of the chapter title and whether it refers to issues of aging with autism or to adjusting to changes in knowledge and practice as science advances. Ms. Blackwell clarified that the committee's intent was the former. It was also noted that the aspirational goal and objectives for Question VI do not make it really clear that the aim of the chapter is to enhance services for adults and those transitioning to adulthood. The meeting closed with an encouragement for the panel to continue to think about these issues and share ideas via e-mail over

the next week. The next meeting is scheduled for Monday, September 21st from 10:00 a.m. to 12:00 p.m.

Action Items:

- Draft suggestions for short-term and long-term objectives in Question V (All panelists)
- Re-draft specific objectives and/or opportunities in Question V (Select panelists)
- Review Question VI and suggest additions and/or edits (All panelists)