

Conference Call #3 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 24, 2009

Call Participants: Ms. Ellen Blackwell (Co-Chair), Ms. Christine McKee (Co-Chair), *Panelists:* Mr. Tec Chapman, Dr. Peter Gerhardt, Ms. Ann Gibbons, Dr. David Mandell, and Dr. Marjorie Solomon; Dr. Susan Daniels (Office of Autism Research Coordination (OARC) Staff)

Summary:

Dr. Daniels welcomed the Panel 5 participants and conducted a roll call. The panelists noted that the finalized slides for the presentation were due to the Office of Autism Research Coordination (OARC) on Monday, September 28th. The group began by discussing the public comments received in response to the Request for Information (RFI), noting that many of the comments related to services and supports for low-functioning adults, access to services, and systems collaboration. The panelists also discussed whether they should incorporate references to underserved rural populations in their suggested revisions to Question V and VI (QV and QVI). Dr. Chapman had developed a passage about service system goals and the panelists agreed that discussion of access in rural areas could be incorporated into the language of this passage. Ms. Gibbons suggested that they mention new opportunities offered through telemedicine and web-based services which could improve access for underserved populations. Dr. Gerhardt pointed out that all aspects of adult life – not just academic achievement – need to be considered in developing appropriate interventions for adults and assessing how well those interventions are working. Ms. Blackwell said that she also wanted to discuss whether to develop an objective on the use of psychotropic drugs for adults with ASD, based on the comments related to the subject in the RFI.

The panelists then reviewed the document developed by Ms. Blackwell which incorporated the edits to QV and QVI discussed during the previous conference calls. While reviewing short-term objectives, Ms. Blackwell reported that the Centers for Medicare and Medicaid (CMS) had initiated the State of the States assessment and that she had readjusted the recommended budget (from \$630,000 to \$700,000). The committee discussed editing the next objective about assessing access to services and its effect on family functioning in “diverse populations” to include underserved populations in rural and inner city areas. The panel recommended reducing the \$1 million budget estimate for this objective. The panel discussed the next objective to support a series of promising practices briefs that describe innovative services and supports being implemented in the community (this could include briefs on successful models of self-employment and micro-enterprises). The panelists noted that “promising practices” would include only services/supports with pilot data suggesting their effectiveness, and therefore would never include dubious practices that could potentially be harmful.

The panelists then discussed Question V’s long-term objectives and noted that the number of studies assigned to each objective (“at least four studies”) seemed arbitrary. The group recommended taking out the number of studies, although Ms. Blackwell explained that the numbers had been used to estimate the budgetary requirements for each objective and would most likely remain in the Strategic

Plan. The group agreed to add “across the spectrum” to the first long-term objective to make it more inclusive of all functional levels.

The panel then discussed the next objective to “test four methods to improve dissemination of effective interventions in diverse community settings.” This evolved into a discussion of the distinction between “interventions” and “services and supports.” Ms. Blackwell said that CMS included interventions in the phrase “services and supports,” and described interventions as “something you get to help you condition,” while services “help you live with your condition.” Dr. Mandell described services as the vehicle for delivering interventions. The group ultimately decided to use the phrase “evidence-based interventions, services, and supports” to encompass all aspects of the area and agreed to discuss the distinction in their presentation. The panelists expanded long-term objective two to include “implementation and sustainability,” in addition to dissemination. Based on public comment through the RFI, the group added a third long-term objective to “develop, if necessary, and test ASD services guidelines and training strategies to increase skill levels for service providers to the spectrum of people with ASD including direct support workers, education staff, and public service workers.”

The panelists discussed Mr. Chapman’s proposed research opportunity related to assigning and training a single case manager to coordinate all of an individual’s services and supports, thus eliminating the complexity of interacting with multiple case managers. He also drafted language recommending resources for family-directed supports. The panelists discussed how self-directed services empower people with disabilities to make active decisions about their care. Noting that some of the committee was probably unfamiliar with the concept of self-directed care, the panelists decided to include a slide in their presentation to provide context.

The panelists discussed the revised title for Question VI: What does the future hold for *the spectrum of adults with ASD*? and decided that transitioning youth preparing for adult services was implied in the title. After discussion, the aspirational goal was amended to: “All adults on the spectrum will have the opportunity to lead self-determined lives in the community of their choice through work, community participation, satisfying relationships, and access to individualized necessary services and supports.”

The panelists discussed the short-term objectives for Question VI and decided to add a separate objective calling to develop a method for identifying adults across the autism spectrum who have gone undiagnosed or who have been misdiagnosed, in order to identify their unmet needs. This objective could possibly be accomplished through existing CDC tracking studies. The panelists recommended striking the existing objective calling to merge or link databases that allow for tracking the involvement of people in ASD research. A cost-effectiveness component was added to the objective calling for comparative effectiveness research examining the impact of interventions, services, and supports on adults with ASD.

The panelists recommended conducting a study to measure and improve the quality of care being provided by specially-trained direct care staff, in the short-term; then conducting a long-term demonstration to successfully implement these training practices. The panel recommended that the

long-term database objective be struck. They then discussed how to best design a study measuring the impact of early interventions on reduction of cost in adulthood, noting the inherent unreliability of retrospective studies on this topic (studies can be affected by recall bias, attribution bias, and the tendency to only report positive outcomes). The panel recommended collaborating with current and recent studies of children and adolescents to continue to follow the subjects into adulthood with the goal of examining how interventions delivered in childhood lead to adult outcome.

The panel discussed including an objective on the appropriateness and effectiveness of psychopharmaceuticals for adults with ASD, and their effects in combination with medications for other co-occurring disorders (such as epilepsy). Ultimately, the panel felt that this should be categorized as a research opportunity and should be discussed with Panel 4, whose members are working on Strategic Plan Question IV: What treatments and interventions will help?

The panel discussed the format of their 45-minute presentation and decided to appoint one panelist to present on Question V, and another to present Question VI. Presenters will be selected after the call. Ms. Blackwell explained that the revisions to the language of the plan would be passed along to the IACC Planning Subcommittee, who would then share its recommendations with the full IACC. Ms. Blackwell volunteered to develop the PowerPoint slides for the Workshop for the rest of the panel to review, as well as to collect and integrate all their recommended edits to the language of the Strategic Plan for presentation to the Planning Subcommittee. Panelists agreed to do any further revisions via email.

Ms. McKee advised removing references to “cost-effectiveness” from the aspirational goals and suggested reviewing the goals once more before finalizing their recommendations. The call was then adjourned.

Action Items

- Refine language of several objectives (Whole Panel)
- Integrate language from selected panelists into “What do we need?” and “What do we know?” (Ms. Blackwell and panelists)
- Collect and integrate all recommended edits to Strategic Plan text, to be sent to panelists for review (Ms. Blackwell)
- Send draft slide presentation to panelists for review (Ms. Blackwell)
- Select two presenters for Scientific Workshop (Whole Panel)