

## **Conference Call for Interagency Autism Coordinating Committee (IACC) Scientific Workshop Panel Four**

Strategic Plan Questions IV: *“Which treatments and interventions will help?”*

Friday, September 18, 2009

**Call Participants:** Tom Insel (Co-Chair), Stephen Shore (Co-Chair); Panelists: Joyce Chung, Bryan King, Edwin Cook, Sharisa Kochmeister, and Robert Hendren; Susan Daniels (Office of Autism Research Coordination (OARC) Staff)

### **Summary:**

The panelists introduced themselves and Dr. Insel, co-chair, began by reviewing the IACC’s charge to annually update the IACC Strategic Plan from Autism Spectrum Disorder (ASD) Research. The method to update the Strategic Plan is to identify any gaps in the current plan, any new opportunities that might exist, and to prioritize the strategic plan objectives. Dr. Insel stressed that this panel is focused on ASD intervention research, and is not tasked with rewriting the current plan, or designing a new one. The suggested edits should conform to the format of the original plan. Dr. Shore, co-chair, added that the panel’s purpose is to provide small changes to the current version. Dr. Insel also pointed out that American Reinvestment and Recovery Act (ARRA) funding information will be released shortly, and that some funding has been allocated to ASD intervention research.

The panel began discussing the gaps that exist in the current version of the Strategic Plan. Ms. Kochmeister raised the issue of highlighting research in both ASD communication and assistive communication technology. Dr. Chung added that studying technologies related to communication or other behaviors is crucial, as the technology field is changing rapidly, and is used by so many people. The panel debated on whether this topic should be highlighted in Short-Term Objective #1 (core symptoms research), Short-Term Objective #4 (school aged and adolescent interventions), or Short-Term Objective #6 (safety and efficacy of interventions).

The panelists also discussed the need for better information on treatments, specifically about their efficacy and effectiveness. Many parents are spending money and time on treatments that have not been proven. In order to make informed treatment decisions, parents and clinicians need reliable information about treatment efficacy/effectiveness, as well as how long to pursue treatments that are not yielding results before they change strategies. The panelists decided that this idea – the need for a better evidence base for treatments to inform consumers - falls into the What Do We Need? section of Question IV, but should also be highlighted in more detail in Short-Term Objective #6.

In discussing treatment efficacy/effectiveness, the panelists agreed that one component to ASD treatment is recognizing that people will react differently to the same treatments, and that creating a personalized treatment protocol that combines effective treatments is important.

Another gap discussed by the panel was therapies for sensory integration. It was not known if any randomized controlled trials for sensory integration therapies existed, so the panel agreed to look into this issue further before the next call.

Dr. Cook brought to the panel's attention that the discussion of biomarkers in Question IV should be modified to include all predictors, not just the limited, specific examples listed in the What Do We Need? Section (plasma, saliva, CSF or tissue). The panelists agreed that the biomarker discussion in this section of the plan needs to focus on predictors of treatment response, not biomarker identification. General predictors including biological signatures, behavioral phenotype and family history should be considered. It was also suggested that the need for a personalized treatment should be highlighted.

The panelist moved on to determining any new opportunities in ASD intervention research. Dr. Shore mentioned that one new intervention approach, the Miller Method, compares available treatments and allows the families and caregivers the opportunity to make informed choices on interventions. This comparative treatment method utilizes aspects of personalized medicine. Dr. Insel informed the panel that the current Administration has placed comparative effectiveness research as a high priority for ARRA funding, though for ASD, this approach might be premature. It was suggested that comparative studies could be highlighted in the Strategic Plan under the objectives that involve randomized controlled trials (RCT), and that some trials could be planned as head-to-head comparison studies rather than placebo controlled trials.

Another opportunity that the panel discussed was intervention research for the adult and geriatric ASD populations. This is an area that should have been highlighted originally, but seemed to have been overlooked in translating the research opportunities into research objectives. Earlier, Dr. King had noted that safe and effective treatments are needed across the lifespan and that perhaps the plan should be more explicit about developing treatments for the older segment of the population. The panel recommended including adult and geriatric ASD populations in Short-Term Objective #4, as well as increasing the number of studies and funding recommended.

The panelists discussed other potential opportunities, including the issue of highlighting stem cell research, as well as the intermediate translational steps in research between the modeling studies that identify targets and the clinical trials. The panel chose not to highlight stem cell research, but did review different ways to add a translational component to the objectives. One possible option was to highlight the translational component in Short-Term Objective #5 (models to identify intervention targets). Dr. Insel noted that one of the goals of this section was to create a balance between the urgent need to study interventions that are currently available with the need to find new treatment approaches. Dr. Chung asked if the panel might want to think about whether there may be a need for infrastructure to support a larger translational research effort, but the panelists concluded that it may be somewhat premature to do that until more basic science has been done to identify intervention targets, leading toward rational intervention design.

The panelists discussed prioritizing Short-Term Objective #5, as it forms the basis for identifying novel intervention targets. The panel also spoke about putting an immediate emphasis on studies that

examine the safety and efficacy of unstudied, widely used therapies (Short-Term Objective #6), such as the Defeat Autism Now! (DAN) treatment protocols. Dr. Hendren noted that Autism Speaks solicited grants in this area, but that many of the proposed studies were not well designed, and that the National Institutes of Health (NIH) should take a greater lead in this effort.

The panel decided that the most effective method to identify priorities would be to crosswalk the Research Opportunities with the Short and Long Term objectives, and to use this information in discussion at the next conference call. This process would also yield missed research opportunities that correspond to the current objectives.

The meeting closed with an encouragement for the panel to continue to think about these issues and to share any new ideas at the next meeting. The next meeting is scheduled for Tuesday, September 22, 2009 at 9:00 a.m. ET.

#### ACTION ITEMS:

- Identify any randomized controlled trials on sensory integration (All Panelists)
- Draft slides from the meeting summary (Thomas Insel, Stephen Shore)
- Crosswalk Short and Long Term objectives with the Research Opportunities (Thomas Insel, Stephen Shore)