

## **IACC Scientific Workshop Panel 1 Conference Call #1**

Strategic Plan Questions III: "When Should I be Concerned?" Thursday, September 17, 2009

**Call Participants:** Dr. Jennifer Johnson (Co-Chair) and Dr. Yvette Janvier (Co-Chair); Panelists: Dr. Geraldine Dawson, Dr. Rebecca Landa, Dr. Deborah Fein, Ms. Paula Durbin-Westby and Ms. Nancy Wiseman; Dr. Susan Daniels (OARC Staff)

### **Summary:**

The panelists introduced themselves and Dr. Johnson (co-chair) began by discussing the items for discussion on the call, which was to address updating Question I of the current version of the IACC Strategic Plan for ASD research. Ms. Durbin-Westby volunteered to prepare slides for the workshop.

Dr. Janvier suggested discussing gaps in Question I of the Strategic Plan. Referring to the Research Opportunities, Ms. Durbin-Westby said that she found that the research priorities section of the chapter did not consider the issues of adult and teen/adolescent diagnosis. She suggested adding as a research opportunity the development of adult/teens/adolescent diagnosis criteria and instruments. She also suggested that special populations including females and some ethnic groups be considered in articulating the research opportunities.

Dr. Fein noted that current diagnosis of ASD is at the age of 3-4 years to later in childhood. However, AAP guidelines recommend screenings at 18-24 months, but do not have an evidence base to support this practice. She suggested the need to look into current literature and that the lack of an evidence base is a gap. She further suggested a need for autism screening to follow broadband development screening. The panel agreed that currently there is no general developmental screening and double screening is required. Dr. Fein suggested that ideally, early screening could be conducted at 6 months of age using a good broadband screening tool, followed by use of diagnostic tools based on early biomarkers for children under the age of 12 months. The current lack of appropriate biomarkers was identified as a major gap. Ms. Durbin-Westby suggested doing a longitudinal study to identify biomarkers. Dr. Dawson joined the conversation and indicated that she had prepared a document for the panel listing 10 potential gaps. She emphasized 2 of the 10 points: 1) The importance of identifying preclinical markers for ASD risk before children show behavioral symptoms (prior to the development of more severe disability), 2) The need to make the aspirational goal more ambitious – to change the goal to identify children with ASD by 18 months of age instead of 24 months.

The panel discussed diagnosis training programs for physicians as a gap and broadband screening to identify developmental delays from birth to 3 years as an opportunity. Ms. Durbin-Westby pointed out that ASD adults are misdiagnosed as mentally/intellectually disabled instead of autistic. Dr. Johnson responded by suggesting that the group organize the objectives using a lifespan construct or framework. Although lifespan issues are mentioned in the research opportunities, they did not translate into the research objectives.

Ms. Durbin-Westby voiced concerns about the ethical legal and social implications of early diagnosis and suggested that this be pursued as a research gap. Dr. Janvier discussed the need for specific tools for different age groups in a community setting. Dr. Dawson suggested that the need for tools to address cultural, financial, language barriers to diagnosis is an important gap.

The panel agreed to incorporate the following additional gaps to Dr. Dawson's list of gaps; #2 "Examine sensitivity and specificity for autism specific broad band screening tools", #12 "Identify to consider ways of addressing a wide range of ethical issues that arise related to the genetic, environmental and clinical risk factors" and #13 "Examine generalized ability of screening tools and other early risk markers that are identified in infant siblings or other high risk samples to general population samples". The panel agreed to keep gap #7 from Dr. Dawson's document specific for adults and adolescents. Dr. Dawson suggested refining gap # 3 to "Understand predictive relationship between early signs and symptoms of ASD risk and developmental trajectory, including autistic regression in both high-risk and population-based samples".

The panel discussed other essential topics that concerned panel 1 such as 1) correct diagnosis of autism in the presence of co-occurring conditions and 2) services following comprehensive diagnosis of ASD individuals (including recovered and regressed children). Ms. Durbin-Westby stated that the panel should focus on reducing disability related to co-occurring conditions and should emphasize activities that would improve quality of life for individuals with ASD. The panel agreed to save the above points as notes for panelists of other questions at the workshop.

Dr. Janvier initiated a discussion regarding changing the wording of the aspirational goal to include early diagnosis and early intervention prior to 24 months of age. After discussion, the panel agreed to change the aspirational goal to "Children at risk for ASD will be identified during the preclinical stage before ASD behavioral characteristics are present and individuals who have ASD will be detected at the point when ASD characteristics are observable across the lifespan".

The meeting closed after the panelists' assigned short term and long term objectives for the possible gaps in Dr. Dawson's document. The next meeting is scheduled for Tuesday, September 22<sup>nd</sup> from 1:00 PM to 3:00 PM

#### Action Items:

- Circulate Dr. Dawson's document among the panelists
- Review Dr. Dawson's document for the next meeting
- First draft of the slides to be prepared by Ms. Durbin-Westby
- Visualize slides on the next call as a webinar