IACC Scientific Workshop Conference Call #2
Panel 1: "*When Should I Be Concerned?"*
Tuesday, September 22, 2009

Call Participants: Dr. Jennifer Johnson (Co-chair), Dr. Yvette Janvier (Co-chair), Dr. Rebecca Landa, Dr. Deborah Fein, Ms. Paula Durbin-Westby, Ms. Nancy Wiseman; Dr. Susan Daniels (OARC staff)

Summary:

Dr. Daniels welcomed the Panel II participants to their second conference call and Dr. Cathy Lord, who had not attended the first call, introduced herself to the group. During this call, panelists were expected to come to consensus on issues about the presentation discussed over e-mail since the first conference call, in order to finalize their preparations for the Scientific Workshop. Ms. Durbin-Westby had put together a draft of the presentation slides based on the discussion during the first conference call, and had provided her own alternative language in parts of the presentation, for consideration by the panel.

The panel reviewed the revised aspirational goal, which had been developed based on the recommendations of Dr. Dawson during the first panel call:

> *"Children at risk for ASD will be identified during the preclinical stages 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."*

Ms. Durbin-Westby had presented an alternative aspirational goal, which stated that children with ASD would be identified by 24 months or when ASD characteristics could be "reliably observed." Ms. Durbin-Westby explained that her constituency from the Autistic Self-Advocacy Network did not recommend the emphasis on preclinical diagnosis because there was potential that reliable and prenatal detection could lead to selective abortion to "prevent" ASD. Ms. Wiseman stated that it was important for the research community to continue to pursue biological indicators present in children before behavioral characteristics arise, a goal lost in Ms. Durbin Westby's alternative wording. The majority of the panelists supported the emphasis on preclinical identification (before behavioral symptoms are observable), and so chose Dr. Dawson's wording, but incorporated that children at risk for ASD will be "identified through reliable methods."

The panel discussed incorporating points on ethical considerations and the prevention of negative outcomes (e.g. severe disability), rather than ASD itself, in other portions of the presentation. Dr. Janvier said that the reference to children "at risk for ASD" was meant to be more inclusive of children showing early risk factors. Ms. Durbin-Westby said that she was also concerned with conveying the idea that autistic characteristics needed to be treated or prevented. The group agreed that the aspirational goal did not directly relate to these ideas and moved to review the research gaps.

The panel requested further information on what constituted a research gap and was told that any research area that had not been included in the 2009 Strategic Plan would be considered a gap. These gaps would be "big-picture" ideas, such as including more females in diagnostic studies, and would be

important to include in their Workshop presentation. Dr. Fein noted that the panel had addressed many of the potential gaps mentioned by the public in the Request for Information (RFI). The panel decided to review the specific numbered objectives proposed by Dr. Dawson in her document, and then identify gaps by comparing these objectives to the existing Strategic Plan.

The panel finalized their short-term objective #1: "Determine the sensitivity and specificity of broad band versus autism-specific screening tools in both high-risk and population-based samples," but noted that most practitioners do not use broad band screening tools.

The panel accepted the existing language for objective #2 and changed #3 to: "Determine the generalizibility of early risk/trait markers and developmental trajectories identified in the infant siblings and other high risk samples to general population samples."

The panel edited objective #4 to call for the development and validation of screening and diagnostic measures for the detection of people with "more subtle forms of ASD," which they felt was a more inclusive descriptor than "high-functioning ASD and Asperger Syndrome."

For objective #5, the panel used Ms. Durbin-Westby's wording to include "variability of autistic traits" and shortened the sentence to:

> *Develop methods for screening and diagnosis of co-existing medical conditions in ASD for children and adults and understand the relationship between the presence of such conditions, variability of autistic traits, and functional outcomes.*

Objective #6, calling for ASD screening and diagnostic tools for adolescents and adults, was incorporated into objective #4. Objective #7 remained unchanged and the panel decided that objective #8, added by Ms. Durbin Westby, to develop "*accessible outcomes measure oriented around more meaning metrics than 'reduction of autistic characteristics*,'" was more appropriate to bring up during the Panel VI discussion of outcome measures, rather than include in the Panel I presentation.

Objective #9, #10, and #11 remained the same and objective #12 was edited to:

> *Identify and consider ways of addressing the wide range of ethical and clinical issues related to the diagnosis, assessment, and communication of genetic, environmental, and clinical risk for autism.*

Ms. Durbin-Westby had proposed calling for a study of ethical, legal, and social issues (ELSI) of early diagnosis, but the group felt that the language should call for a broader array of ethical and clinical issues.

Objective #13, proposed over e-mail during the discussion between the last call, was added:

> *Provide supplementary funding to the NIH National Children's Study to enhance the current design so that the relationship between genetic and environmental risk markers and ASD diagnosis can be studies in a population-based sample.*

The panelists began discussing the proposed long-term objectives, keeping the wording of objective #1 and developed the final language for objectives #2 and #3:

> Long-term objective #2: *Understand the predictive relationship between early signs and traits of ASD risk and developmental trajectory and outcomes in both high-risk and population-based samples.*
>
> Long-term objective #3: *Determine prevalence of and factors associated with changes in core features (behavioral, biological, cognitive) of ASD.*

The panelists discussed the logistics for panel presentation and nominated Dr. Dawson to present with Ms. Durbin-Westby. Ms. Durbin-Westby volunteered to finalize the PowerPoint presentation and send to the group for approval.

Action Items

- Identify gaps by comparing recommended objectives to the existing plan (Whole panel)
- Finalize PowerPoint and distribute to the panelists for approval (Ms. Durbin-Westby)
- Prepare presenters for the Scientific Workshop (Liaisons)