2009 IACC Scientific Workshop:

Updating the Strategic Plan for Autism Spectrum Disorder (ASD) Research

September 30 - October 1, 2009

Bethesda, Maryland

Panel 1: “When should I be concerned?”

- Clinical Experts
    - *Geraldine Dawson, Rebecca Landa*
- Research Experts
    - *Deborah Fein, Catherine Lord*
- Family/Personal Experts
    - *Paula C. Durbin-Westby, Nancy Wiseman*
- Coordinated by IACC Liaisons
    - *Yvette Janvier, Jennifer Johnson*

Panel 1: Revised Aspirational Goal

- *Children at risk for ASD will be identified through reliable methods during the preclinical stage before ASD behavioral characteristics are present and people who have ASD will be detected at the point when ASD characteristics are observable, across the lifespan.*

For Discussion Purposes Only

Panel 1: Noted Research Gaps in the 2009 IACC Strategic Plan

- *The need for early diagnosis in children is the main emphasis in the current plan; this should be broadened to include identification across the lifespan and in diverse groups (females, minorities).*

Panel 1: Short-Term Objectives

1. Determine the sensitivity and specificity of broad band developmental screening versus autism-specific screening tools in both high risk and population-based samples.
2. Develop and validate effective screening tools for infants at risk for ASD below age 18 months.
3. Determine the generalizability of early risk markers and developmental trajectories identified in infant siblings and other high risk samples to general population samples.

For Discussion Purposes Only

Panel 1: Short-Term Objectives (Continued)

4. Develop and validate screening and diagnostic measures for detection of people with subtle characteristics of ASD.
5. Develop methods for screening and diagnosis of co-occurring medical conditions in ASD and understand the relationship between these conditions, ASD characteristics, and short and long term outcome.
6. Develop effective ASD screening and diagnostic tools for use with adolescents and adults.

Panel 1: Short-Term Objectives (Continued)

7. Understand and identify methods to address barriers to early screening and detection of ASD among ethnic minority populations.
8. Understand factors that impede or promote the use of ASD diagnostic and screening tools in community settings (e.g. pediatricians in general practice).
9. Develop and test the efficacy of programs to train practitioners in the use of ASD screening tools and in effective, respectful, and positive communication with families following a positive screen or diagnosis.

Panel 1: Short-Term Objectives (Continued)

10. Investigate the extent to which early diagnostic evaluation leads to appropriate early interventions.
11. 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, as well as the social and clinical effects of diagnosis on the child and family.
12. 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 studied in a population-based sample.

Panel 1: Short-Term Objectives (Continued)

13. Creation of a coordinated data base of clinical and biological information on existing samples of high-risk infant siblings (such as the Baby Siblings Research Consortium) to allow research on the relationship between genetic and other biological signatures, early screening and diagnosis, and long term diagnostic outcome in ASD.

Panel 1: Long-term Objectives

1. Identify preclinical markers of risk for ASD.
2. Understand the predictive relationship between early signs and symptoms of ASD, including preclinical risk markers, developmental trajectory, and outcome in both high-risk and population-based samples.
3. Determine the prevalence of and factors associated with changes in core features of ASD.

Panel 1: Summary & Discussion Questions

- Revise aspirational goal to reflect efforts toward reliable detection of ASD at younger ages and throughout the lifespan.
- Develop and validate screening tools for a wider range of populations including younger children, adolescents and adults, and people with subtle characteristics.
- Evaluate broad-band developmental screening to identify ASD.
- Develop methods for screening and diagnosis of co-occurring medical conditions.

For Discussion Purposes Only

Panel 1: Summary & Discussion Questions (Continued)

- Define barriers to the use of screening and diagnostic tools in ethnic minority populations and in community settings.
- Develop and evaluate training programs for professionals and evaluate whether diagnosis leads to intervention.
- Address the wide range of ethical issues related to screening and diagnosis.