

**Summary of IACC Strategic Plan Question 4 Working Group – Conference Call #1
September 23, 2016; 4:00pm EDT**

Welcome and Introductions

Working Group Members in Attendance:

Kevin Pelphrey – Co-Chair
Alice Kau
Connie Kasari
James Ball
Timothy Buie
Alexander Leonessa
Frederick Shic
Christy Kavulic
Phillip Strain
Denis Sukhodolsky
Tiffany Farchione
Elizabeth Laugeson
Louis Reichardt
Alex Kolevzon
Beth Malow
Nancy Minshew
Samuel Odom
Mustafa Sahin
Zachary Warren

Working Group Members Absent:

Samantha Crane
Geraldine Dawson
Melissa Harris
Elisabeth Kato
Robert Ring
David Mandell

Summary of 2013 Portfolio Analysis – Group Discussion (Pages 1-4, Data Analysis Slides)

1. Comments/observations on the overall portfolio?

- Working group members noted that calculating average funding per project by subcategories would be a good way to get a sense of newer, emerging areas of research versus more well-established fields.
- There was discussion about projects studying animal model systems for the development of therapeutic targets and whether in future years those projects should be included under Question 2.
- Working group members thought it would be important to also consider what projects have been funded since 2013, as well as scientific publications that may have resulted from previously funded projects. As an example of more recently funded projects, the Department of Defense has since shifted its focus to services and has reinstituted clinical trial awards in pertinent areas.

- There was also interest in looking at the project abstracts and considering projects by the age groups targeted as well as the type of intervention or treatment studied, although there was also recognition that some projects are broad and not targeted to a specific age group.

Analysis of Question 4 Objectives (Multiyear Funding Table and 2013 Project List)

1. Has there been an adequate number of projects for each objective?

- Following discussion about how such specific recommended numbers of projects were included in the previous Strategic Plan's objectives, the working group agreed that objectives in the new Strategic Plan should likely be broader and not as restrictive. The new objectives could represent goals of where the IACC would like to see the field go, and examples of the kinds of projects recommended could be included under each broad objective.
- Some working group members also wanted to look more closely at the multi-site projects within the 2013 portfolio to get a full grasp of the variety of projects that have been undertaken.

2. For each objective, do the funded projects cover the scope of the objective? Any noted areas of progress or gaps?

- Working group members noted it will be important to consider exactly which projects from the 2013 portfolio were truly randomized clinical trials, which were pilot projects, and which have been completed. This will help the working group gain a better sense of which randomized clinical trials are still needed.
- Working group members remarked on the importance of the National Science Foundation's (NSF) portfolio of funded research in this Question area. When developing the new Plan, it may be useful to consider strategies for enabling more collaboration between NSF and the National Institutes of Health (NIH), especially on the translational component of technologies, as well as facilitating the translation of NSF-funded projects to more applied, NIH-funded projects.
- Many of the current interventions are dependent on academic centers and academic level staff to facilitate delivery. More work is needed to develop community-friendly or school-friendly sites as well as community professionals in order to improve implementation, dissemination, and the ability of more families to access treatments and interventions.

3. Was the recommended budget for each objective reached? If less was spent, but the number/scope of projects was appropriate, should the objective be considered completed but accomplished with less than the expected budget? In cases where more was spent than the recommended budget, was it because many more projects were funded in that area or because projects were more costly than originally projected? Are there any concerns with regard to funding associated with objectives?

- There was a question about why some projects included in the 2013 portfolio had an associated budget of \$0. These projects were ongoing in 2013 but did not receive any of their project funding in that year.

4. Does the working group observe any areas of this question or specific projects that appear to be duplicative? Does the working group have suggestions about how duplication of effort can be avoided in this area?

- The working group felt it would be important to differentiate harmful duplication from valuable studies that attempt to replicate findings. In contrast to concerns about duplication, direct and systematic replication of treatment studies is useful, and more replication studies are needed. The working group will consider the IACC's response to a previous Government Accountability Office report on potential duplication in autism research.

5. Are there areas of emerging research that do not appear to be represented strongly in the portfolio that should be considered for mention in the new Strategic Plan?

- Areas identified by the working group for inclusion or additional emphasis in the next Strategic Plan included:
 - The effect of gender differences in autism, especially in treatment response
 - The development of interventions in educational settings
 - Innovative strategies for combining pharmacologic and behavioral interventions
 - The importance of accelerating the pace of research, enabling personalized medicine approaches, and developing strategies for disseminating treatments and interventions (to whatever extent it can apply to Question 4 or be included in Question 7)
 - Stratification by neurocircuitry
 - Microbiome, metabolome, and treatment for intestinal overgrowth, although this may need to be coordinated with the chapter on Question 2
 - A greater involvement of individuals with autism in Question 4 research and issues; involving adults with autism in the planning of treatment research
 - Studies that address behavioral changes, early indicators of treatment response, moderators, active ingredients, and objective outcome measures
- It may be useful to think about interventions by organizing them by those that target core symptoms and those that target associated symptoms. These could be further divided by behavioral/cognitive versus pharmacologic, and then further divided by the age groups targeted.

Wrap up and preview of next call

- On the next call, the working group will discuss recent advances in research, services, and policy.