

**Working Group 6 – Conference Call #1 Summary  
September 20, 2016; 2:00pm EDT**

**Welcome and Introductions**

Working Group Members in Attendance:

Julie Taylor – Co-Chair  
JaLynn Prince  
Robyn Schulhof  
Leslie Caplan  
Vanessa Hus Bal  
Samantha Crane  
Edlyn Peña  
Somer Bishop  
Nancy Cheak-Zamora  
Laura Klinger  
Paul Shattuck  
Scott Badesch  
Amy Goodman  
Susan White

Working Group Members Absent:

Brian Parnell – Co-Chair  
Ophelia McLain  
Nancy Spencer  
Kevin Pelphrey  
Alison Singer  
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 discussed the small proportion of projects categorized to Question 6 compared to the rest of the portfolio. Question 6 is the least represented research area, yet it represents the largest portion of the lifespan. There was discussion revolving around which funders are funding this area and if some funders could be funding more in this area.
- It was noted that while Question 6 is the least funded question in the portfolio, the topic has received more attention in recent years, and it is likely that funding for Question 6 has increased since 2013, though the data for 2014-2016 are not yet available. Also, it is important to consider private organizations that are not included in the IACC Portfolio Analysis that are funding projects and programs in this field. Though several private organizations participate in the Portfolio Analysis effort, some organizations have opted not to participate, and there may be others that should be invited to participate in the future.

**Analysis of Question 3 Objectives (Multiyear Funding Table and 2013 Project List)**

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

- Several members of the working group noted the lack of projects in Question 6's overall portfolio. An emphasis on the need to see an increase in larger-scale projects which require larger budgets should be noted in the next Strategic Plan.

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

- Suggestions for rewording Objective 6.L.C to state "community living and housing" or "community integration" rather than "community housing" were mentioned. The overall goal of Objective 6.L.C was to enable community inclusion; the terminology should be updated when this topic is considered for the new Strategic Plan objectives.

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?

- Working group members discussed the need to not only increase funding in this question area, but to also increase focus on impacts and outcomes. Unless research is impactful, an increase in research funding does not necessarily mean outcomes would improve in adulthood; it is important to increase the return on funding that is already being spent in terms of community benefits. In addition, the working group members agreed the next Strategic Plan should address the need for increasing the number of projects and funding, and also focus on research that has impact.

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?

- There was a concern for the categorization format which made it difficult for some to evaluate certain categories of the research portfolio; for example it was difficult to separate research on teenagers from research on adults.

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 that should be considered for inclusion or additional emphasis in the next Strategic Plan included:
  - Research on quality-of-life indicators
  - Health outcomes research at different stages of life
  - Long-term effects of medication
- When formulating the new objectives, there was discussion about creating objectives that focus on separating transition to adulthood from adult services in general rather than having objectives by specific kind of service.

### **Wrap up and preview of next call**

- The next call will include a discussion of input received through the Request for Public Comment.
- The next call will also include a discussion of research updates since the development of the last Strategic Plan. Working group members are encouraged to send examples of any scientific breakthroughs for discussion on the next Working Group 6 conference call.