

**Conference Call for Interagency Autism Coordinating Committee (IACC) Scientific Workshop Panel Five**  
Strategic Plan Questions V & VI: *“Where can I turn for services?”* and *“What does the future hold?”*  
Monday, September 21, 2009

**Call Participants:** Ms. Ellen Blackwell (Co-Chair), Ms. Christine McKee (Co-Chair); Panelists: Mr. Tec Chapman, Ms. Ann Gibbons, Dr. David Mandell, Dr. Cathy Pratt and Dr. Marjorie Solomon; Dr. Susan Daniels (Office of Autism Research Coordination (OARC) Staff)

**Summary:**

Ms. Ellen Blackwell, co-chair, began by instructing the panel to use the Request for Information (RFI) documents sent by Dr. Daniels in their discussion of Questions V and VI. Ms. McKee, co-chair, noted that Dr. Sam Odom presented a list of evidence-based practices at the IACC Services Subcommittee meeting on September 15, 2009, and that the panel should review his presentation.

The panelists started discussing the title of Chapter VI, and agreed to modify it to read “What does the future hold for adults with Autism Spectrum Disorder (ASD)?”, as adults need to be addressed specifically. They also discussed points raised in the RFI, including the frustrations among families of people with severe communication problems. Dr. Pratt pointed out that one should not assume that needs for services are greater for those who are “low functioning” versus “high functioning.” The discussion then shifted to the Research Opportunities in Question VI.

In discussing Research Opportunity #1 (longitudinal studies examining elements of ASD heterogeneity) the panelists decided that it is important to mention that people with ASD can have very different outcomes, and that due to the difficulty in identifying autistic adults who may be leading mainstream lives, the medical lifespan issues of this population remain unknown. The Research Opportunity will be modified to reflect this need to better understand the adult population of people with ASD.

While the panel discussed Research Opportunity #2 (scope and impact of ASD for adults), the panelists noted that there were two main ideas missing: (1) that of a personalized intervention approach, and (2) an outcomes measure of quality of life. Specifically, the personalized intervention approach should include an individual, “needs-based”, assessment, and that this assessment is specific to the individuals across the spectrum, and requires integration with diagnosis. These personalized interventions may also come from using a “self-directed” service option. Language on these points will be added to the Research Opportunity. Mr. Chapman raised the point that one other measure of outcomes could include economic self-sufficiency.

Dr. Mandell suggested that the panel consider adding more Research Opportunities that can be operationalized in the Short and Long Term Objectives, as is done in Questions I-IV of the Strategic Plan. These additional Research Opportunities could result from separating ASD subgroups, such as those with communication deficits, those that are considered low-functioning, and those that utilize a self-directed option for services. This point was debated by the panel, who agreed to the importance of the

mentioning of specific subgroups, though no conclusion was reached. It was also suggested that Research Opportunity #2 could be broken into a number of bullets that include components of the location and status of people with ASD, diagnosis, a needs outcomes measurement, inclusion of more research, and the improvement of the quality of life for ASD individuals.

The panel moved on to discussing Research Opportunity #3 (use of administrative database), and agreed that the phrasing described a source rather than a scientific question that could become a Research Opportunity. The concerns raised by the panel about this Research Opportunity included that other opportunities may be more important to focus on, and that though administrative databases are an important feature in research, often times their data is not a representative sample. The panel concluded that the critical research opportunity represented here is the ability to locate adults with ASD and investigate their current condition (e.g. housing, medical). The panel also discussed the use of administrative databases, and it was suggested that it is important for these databases integrate adult diagnostic data as well as individualized services. Ms. Blackwell suggested that this Research Opportunity should be modified, along with its corresponding Short and Long Term Objectives.

In discussing additions to the Research Opportunities, Ms. Blackwell mentioned that training for direct care staff to help improve the quality of life for adults could be considered. Dr. Pratt suggested that research may be warranted on whether having trained staff available for adults with ASD makes a difference. Ms. Blackwell added that cost effectiveness studies (e.g. looking at the cost effectiveness of staff training – to see if it helps staff retention) may be another important topic for research. The panel debated ways that could be used to accomplish this, including study of state-wide services training programs, as demonstration projects, or research studies. The metrics to be used to evaluate the studies should be the quality of life from the perspectives of both the trainers and the trainees, cost-effectiveness, and programmatic sustainability. The panel agreed that this should be a new objective.

The panelists decided to add quality of life as a metric for Short-Term Objective #2 (variations in adults living with ASD).

In discussing the meaning of the term “legal status” in Short-Term Objective #2, the panelists shared the belief the Research Opportunities, Short-Term or Long Term Objectives need to explicitly mention systems research that supports adults with ASD. These systems should include Medicare and the penal system, as well as including interagency coordination. This idea should also be added to Question V.

The panel discussed modifications to the wording of Short-Term Objective #3 (efficacy and cost-effectiveness of interventions for adolescents and adults), including changing the wording of the types of studies from “randomized controlled trials” to “studies”, “demonstration projects”, “randomized trials”, or “field trials,”. Dr. Mandell mentioned that the term “RCT” indicates an experimental design, which is critical. Dr. Mandell agreed that some studies that are not RCTs (i.e. experimental or quasi-experimental studies). This type of research could also include comparative-effectiveness studies that compare different treatment models. The group recommended striking the words “clinical trials” and

replacing them with “studies”, with the understanding that these studies examine the implementation component as well. They also added a quality of life assessment to the objective.

In discussing Short-Term Objective #4 (conducting a needs assessment on merging and linking databases) the panelists discussed the two separate objectives contained in Short-Term Objective #4; 1) to organize the databases, and 2) to identify the subjects. The objective could also address the question of how ASD manifests in the adult, and what is the best way to support them. The panel noted that this objective would benefit from a rewrite.

Another idea that the panel believed to be appropriate for inclusion in Question VI, was the objective on dissemination of promising practices written for Question V, while being tailored for the adult ASD population.

One other major concept the panel discussed was the need for community acceptance, peer opportunity and training, interaction with non-disabled adults, and participation in mainstream life activities. They decided to modify the Question VI Aspirational Goal, and to include these concepts as well as include them in the Research Opportunities and the Short and Long Term Objectives. Better coordination among Federal agencies was another topic that was discussed, and Dr. Chapman agreed to look into that subject further prior to the next call.

The panel discussed housing for people with ASD, and debated if issues related to housing for people with ASD were unique or relevant to other disabilities. Dr. Mandell also noted that little is known about where adults with autism are living, what happens to adults with ASD as their parents age, and that people with ASD but without severe intellectual disability may actually lack a safety net when their parents become elderly and can no longer care for or assist them. He stated that a “cradle to grave” approach, as employed for other disabilities, might be needed for ASD. The panel decided that the issue of ASD housing (including segregation, institutionalization and ways to address the problem of aging parents) should be highlighted in an objective or a Research Opportunity. An open research question is whether housing is a worse problem for people with autism than it is for people with other disabilities.

The meeting closed with an encouragement for the panel to continue to think about these issues and to make any changes to panel documents using the track change function. The next conference call is scheduled for Thursday, September 24, 2009 at 10:00 a.m. ET.

#### ACTION ITEMS:

- Modify the Research Opportunities for Question VI based on discussions (Marjorie Solomon)
- Rephrase Short-Term Objective #4 based on discussions (Tec Chapman)
- Distribute changes made to Question V to panel (Ellen Blackwell)

- Develop points for panel presentation (Ellen Blackwell)
- Comment on distributed material (Entire Panel)