

**Working Group 5 – Conference Call #2 Summary  
September 26, 2016; 1:00pm EDT**

**Welcome and Introductions**

Working Group Members in Attendance:

Shannon Haworth – Co-Chair  
Samantha Crane  
Melissa Harris  
Larry Wexler  
Lauren Brookman-Frazee  
Robert Cimera  
Daniel Davis  
Leticia Manning  
Cathy Pratt  
Aubyn Stahmer  
Jane Tilly  
Juliann Woods

Working Group Members Absent:

David Mandell – Co-Chair  
Brian Parnell  
Laura Kavanagh  
Anne Roux  
Peter Gerhardt  
Lisa Goring

**Discussion of Public Comments received through Request for Information**

- It was noted adult-based services and services throughout the lifespan were not mentioned in the Question 5 Request for Information, however these topics will be covered in Question 6 (Lifespan Issues).
- There was a discussion on whether the services workforce should be addressed in Question 5 (Services) or Question 7 (Infrastructure and Surveillance). Since the update of the Strategic Plan will have services and policy sections under each question, the services workforce will be better suited for Question 5.
- Although comorbidities were not mentioned in the Question 5 Request for Information, it is important to keep this topic in mind during the discussion of services.
- Working group members were also interested in reviewing comments about ensuring the most severely affected members of the autism community are addressed.

**Discussion of Research Progress**

1. What are the most notable areas of recent progress in this Question's field of research? What new opportunities have emerged?
  - The working group members discussed the progress made in the services research field; there is now an understanding about the types of disparities and barriers to services. Since the research

has identified the gaps and needs of people on the autism spectrum, it is time for the research to focus on addressing these issues.

- While there has been research development on employment services for youth and adults, the topic of employment will be covered in Question 6 (Lifespan Issues).
2. What progress has been made in translating research into practice?
    - It was mentioned that the implementation of behavioral interventions and supports in the education system has been important in keeping children with ASD in a more instructional environment within mainstream classrooms.
    - There has been a growth of research focused on person-centered planning which is ready to be implemented on a larger scale.
  3. What are the most significant barriers to progress in this field?
    - There are issues with the infrastructure of the service system in that the complex needs of the system make it difficult to sustain implementation science. For example, organizations trying to implement evidence-based practices might not be able to maintain the cost to fund these services and supports long-term.
  4. What are the most pressing needs or evidence gaps that can be addressed through research?
    - Working group members discussed the need to develop and build on current demonstration sites to provide infrastructure for implementation science.
    - There needs to be more research on economic outcomes and costs; the availability and access to data is a barrier to enabling research on cost-effective services.
  5. Are there emerging areas of research that need additional support?
    - There has been limited progress on developing long-term supports and services that adapt throughout the lifespan.
    - Disparity research needs to be expanded upon; this includes obtaining data on the different kinds of disparities present in the service system and how to address these disparities to create equal access to services. Telehealth and distant learning for training and service delivery were mentioned as types of tools that should be further developed. There was also a discussion on recognition of disability as a disparity in itself and how that affects individuals' access to services.

### **Discussion of Services and Policy Changes**

1. Are there any innovative programs or recent policy changes that have address some of the gaps or interests of this Question's research area?
  - Currently, some state education systems are undergoing long-term plans that are using implementation science to build ASD services into their current plans.
  - CMS issued a final rule on the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) guide for Medicaid state plans so that states track access to care which will in turn influence the conversation on identifying measures to access for services.
  - In 2014, CMS issued a final rule on defining a home and community-based setting. For children on Home and Community-Based waivers, they will now have to receive long-term services and

supports through a person-centered plan. This will be important for children who are at risk of segregation or institutionalization.

2. Is there new research evidence that can inform the policy agenda?
  - It was mentioned that research by Samuel Odom on scaling up service system infrastructure provides a successful framework for implementation science of services.
3. Are there opportunities for practice to be more actively informing research?
  - There was discussion on the need to have access to databases within agencies already collecting data on service utilization and delivery. Information collected by those agencies can better inform the research agenda on services and supports.
4. What are the most significant services needs or gaps that are not being addressed by current policies and programs?
  - There is a need for more robust ways to measure community-based services.
  - The systems of care model needs to be revisited. There is a need for navigation between service systems so that it is a coordinated, centralized service for the individual with ASD. An example of this is medical homes; there is sufficient research on medical homes but the findings are not easily implemented or coordinated in the community setting.
  - Billing rates and reimbursement are preventing implementation of evidence-based practices.

### **Discussion of Aspirational Goal**

Based on the state of the field, is the **Question 5 Aspirational Goal** still appropriate?

**Communities will access and implement necessary high-quality, evidence-based services and supports that maximize quality of life and health across the lifespan for all people with ASD.**

- There was discussion about changing the end of the Aspirational Goal to “...all people with ASD **and their families.**” This will be further addressed on the next call.

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

- On the next call the working group will discuss new objectives for Question 5 that capture the key ways the field can move forward in services.