Working Group 1 – Conference Call #2
September 27, 2016; 12:00pm EDT

Welcome and Introductions

Working Group Members in Attendance:
Alice Kau – Co-Chair
Ann Wagner – Co-Chair
Shannon Haworth
Nicole Williams
Daniel Coury
Sandy Magana
Karen Pierce
Diana Robins
Audrey Thurm
Amy Wetherby

Working Group Members Absent:
Jennifer Johnson
Ami Klin
Catherine Lord
Angela Scarpa
Debra Wagler
Lisa Wiggins

Discussion of Public Comments received through Request for Information

- It was noted a large amount of comments focused on the need for more research on biomarkers and the use of biomarkers in screening and diagnosis. There was also a substantial amount of comments dedicated to multifaceted disparities in diagnosis. Research on the need for more access to screening services received the lowest number of comments.
- The working group members discussed if research on biomarkers and sex differences should be listed under Question 2 (Biology). The use of biomarkers would be beneficial in diagnosis and treatment, however, current research on biomarkers is at the fundamental stages and its potential as a measurement in diagnosis and treatment remains unclear.
- There is a disconnect between the current state of science and the services system; future research endeavors need to focus on translating science to understand the impact of the applied services field.
- The current state of genetic testing and access to genetic testing should be addressed in the update of the Strategic Plan.

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?
   - There has been progress on the use of biomarkers to identify subgroups. For example, there has been recent developments in the use of eye-tracking studies to diagnosis ASD.

- Within the research field, there has been major advances in screening and early diagnosis, however, these developments have not correlated to community practice, especially in marginalized communities. There is still room for research on translating these tools in the communities and adapting them for racial and minority communities. More research is needed in this area, and specifically on disparities.

2. What progress has been made in translating research into practice?
   - The research field has validated useful screening and diagnostic tools, however timely screening and diagnosis needs to be done in the community without the aid of researchers.

3. What are the most significant barriers to progress in this field?
   - There has been progress regarding recognition of the medical aspects of co-occurring conditions (e.g. GI issues and epilepsy), the importance of managing these health conditions, and that these can perhaps help in the identification of subgroups.
   - Working group members discussed the difficulty of implementing early screening and diagnosis strategies with pediatricians; many pediatricians cite lack of time, feasibility, and knowledge to use these evidence-based instruments during routine visits.
   - Areas identified by the working group as barriers to progress were:
     - Funding allocated for community-based practice research
     - Training and workforce expertise and how it is paid for
     - Services that are not ASD-specific early enough
     - Differences in service implementation by each state
   - The barriers for adults to be screened and diagnosed was mentioned, however working group members agreed this is a question primarily about overall lack of services and access to services for adults rather than specifically revolving around screening and diagnosis. There would also need to be more work on developing tools tailored for screening and diagnosis in adults who have never previously been diagnosed.
   - Many barriers were addressed that revolved around underserved individuals who had been screened trying to receive an early diagnosis. Some of the barriers included:
     - Long waiting lists
     - Inadequate funding
     - Lack of a culturally competent workforce
     - Language barriers
     - Systemic barriers
     - Parent education
     - Diagnostic tools for culturally-diverse backgrounds
   - There was a discussion on how children in minority groups are often diagnosed for a behavioral disorder first, usually in the school setting, and then the ASD diagnosis comes later on.

4. What are the most pressing needs or evidence gaps that can be addressed through research?
   - The working group members debated the need to address the United States Preventative Task Force recommendations on early screening. Many questioned if the study the task force recommended was feasible and if that level of evidence was needed. The working group members concluded it was important to address aspects of the task force's request in the next Strategic Plan.

- There is a need to increase collaboration and training to better understand advances in early screening and diagnosis.
- While there are screening and diagnostic tools that have been developed and validated, we need more specific tools for individuals that are on the higher-functioning part of the spectrum as well as tools that address co-occurring conditions.
- The working group members discussed whether we should be focused on ASD or if there should be a larger focus on intellectual and developmental disability early screening and diagnosis. Members agreed there is an initial need to screen for I/DD and then follow up with ASD-specific instruments.

5. Are there emerging areas of research that need additional support?
   - Emerging areas highlighted by the working group included:
     - The need to increase dissemination products that bring awareness to parents about developmental milestones
     - Support and sustain translating research findings into the community setting

Discussion of Services and Policy Changes

1. Are there any innovative programs or recent policy changes that have addressed some of the gaps or interests of this Question's research area?
   - Working group members agreed the changes in the diagnostic criteria from DSM-4 to DSM-5 have had a positive impact. Recent studies have seen the removal of language from the diagnostic criteria as beneficial, especially in culturally-diverse communities.

2. Is there new research evidence that can inform the policy agenda?
   - Recent studies on parent-report screenings (Robins, 2014) were able to reduce the diagnosis rate to below 2 years old on average in a study environment, however that is not the case in a real-word setting. It would be useful to use studies like this to inform pediatricians and increase implementation in the community.

3. Are there opportunities for practice to be more actively informing research?
   - The ACA calls for autism treatment to be covered; however, many states haven't started covering autism treatments. It would be beneficial to do a policy study looking at what states are performing these requirements and which ones are not and see how it is affecting access to early screening and diagnosis.

4. What are the most significant services needs or gaps that are not being addressed by current policies and programs?
   - States have Part C funding, however these are not ASD-specific. The Part C funding provides a false sense of security when one becomes eligible so many won't seek ASD-specific eligibility. The process to get Part C funding eligibility is a barrier for families and individuals to receive the specific resources they need in a timely manner. Also, there are disparities regarding which families are receiving eligibility.

Discussion of Aspirational Goal

Based on the state of the field, is the **Question 1 Aspirational Goal** still appropriate?

Children at risk for ASD will be identified through reliable methods before ASD behavioral characteristics fully manifest.

- The working group members discussed if the aspirational goal should continue to be focused on biomarkers, especially considering that the current state of the field is unsure if this will ever be achievable.
- The working group members discussed whether the aspirational goal should focus on improving screening detection so no children are missed for early diagnosis, thereby providing the opportunity for the best outcome. The group discussed if this would be more appropriate as a new objective or as a revision to the aspirational goal.
- Further discussion on the aspirational goal will take place on the third call.

Wrap up and preview of next call

- On the next call the working group will discuss new objectives for Question 1 that capture the key ways the field can move forward in screening and diagnosis.