

**Summary of IACC Strategic Plan Working Group for Question 1 – Conference Call #3
November 8th, 2016; 12:30-2:00 pm EDT**

Welcome and Introductions

Working Group members in Attendance:

Alice Kau – Co-Chair

Ann Wagner – Co-Chair

Shannon Haworth

Jennifer Johnson

Nicole Williams

Daniel Coury

Sandy Magana

Karen Pierce

Diana Robins

Angela Scarpa

Audrey Thurm

Debra Wagner

Amy Wetherby

Lisa Wiggins

Working Group members Absent:

Ami Klin

Catherine Lord

Discussion of Chapter Outline

- The question was raised whether research and services will have their own sections within the chapter or be merged together. Based on other chapter's discussions, each working group will identify the major topics for each chapter and discuss the research, services, and policy under each topic.
- Under the discussion on workforce in the chapter, it is important to address training that includes culturally appropriate conversations to help families understand the implications of a screening or diagnosis.
- The working group members discussed the need to address in the chapter the policy implications of giving an ASD diagnosis at 18 months. While research supports a stable diagnosis can be made at 18-20 months, it is a challenge within the community for a diagnosis at that age to be accepted. Members debated if at an early age it is preferable to use terminology such as "displaying signs of ASD" rather than an official diagnosis. Also, the working group addressed the implications of a false positive label for parents. Maybe resolving delays is more important at a young age than requiring an autism label. However, state policies often necessitates an early diagnosis, since some states require a diagnosis to ensure more hours of intervention.
- One working group member provided written feedback saying that although specificity of ASD screening instruments could be improved, almost all false positive results reveal some form of developmental delay that warrants intervention. Therefore ASD screening is important to detect

both ASD and related conditions that add to the complexity of the diagnostic and developmental profile, and should be monitored over time. Of course, improvement in specificity would help improve the diagnostic process and individualized treatment plan.

- Members agreed it might be beneficial to prepare the chapter narrative by beginning with the service needs and how these needs can lead to inform research and policy. This could lead to a way of highlighting the gaps in research, as well as where research is ready to be moved into practice.

Discussion of Proposed Strategic Plan Objectives for Question 1

Areas highlighted on previous calls for possible consideration:

1. Strengthen the evidence base for the benefits of early detection of ASD.
2. Reduce disparities in early detection by removing barriers to access and enhance culturally appropriate outreach efforts.
3. Improve/validate existing, or develop new, tools/methods for detecting ASD to facilitate early and targeted interventions.

1. Strengthen the evidence base for the benefits of early detection of ASD.
 - It was suggested to include in the text that supplements this objective how different study designs can contribute to the evidence base. It is difficult to do Randomized Control Trial (RCT) long-term outcomes, therefore it would be important to discuss how different research designs contribute. Also, this can be a way to address the USPSTF report.
 - It was stated that to improve early detection there must be greater attention paid to special autism populations such as girls and intellectually delayed individuals.
2. Reduce disparities in early detection by removing barriers to access and enhance culturally appropriate outreach efforts.
 - Some of the examples to be mentioned under this objective included:
 - Data demonstrating the validity of different screening and diagnostic tools for culturally-diverse communities.
 - Increase services in high poverty regions and get more people from these areas involved in research.
 - Policy: Addressing differences in state policy requirements for Medicaid and the need for a diagnosis to receive services.
 - Workforce training and improvements in the service system.
 - It was mentioned that there are some grants underway at this time that could address these gaps and concerns, but there are not yet findings to address this. Members agreed not to get into the details about what grants are underway but will plan to mention in narrative.
3. Improve/validate existing, or develop new, tools/methods for detecting ASD to facilitate early and targeted interventions and services.
 - Include in objective language the word “services”: tools/methods/**services**; under this objective there should be the discussion on the handoff to intervention services. There also may be other services that would be helpful.

- Also, it is important to address the continuity of service and interventions. If a family is doing something that is working that they want to retain, or if something needs to be done differently, there needs to be a continuity of treatment based on what is working for the family and what is not working.

Overall input on the objectives:

- Working group members were in agreement that the objectives presented were inclusive, broad, and feasible objectives that will cover the topics addressed in the chapter's narrative.
- The importance to weave in the family perspective into each of these objectives was noted.
- Workforce can be addressed mostly in objective 2 but also through all three objectives.

Discussion of Change to Aspirational Goal and Chapter Title:

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

- On the last call, the group suggested removing the emphasis on biomarkers.
- Members agreed they believed the emphasis of the aspirational goal should be on identifying kids as early as possible, not on biomarkers.
- A suggested change to the aspirational goal was:

“Provide the earliest possible diagnosis for children and adults on the autism spectrum, so they can be linked to appropriate interventions, services and supports in as timely a manner as possible”
- While the goal is to detect and move families faster towards treatment, the intent is not to fast track diagnosis or hold off treatment based on a diagnosis.
- Suggested wording included: “provide earliest possible **detection of risk of ASD...**”; however, some working group members believed it was still important to include the word “diagnosis” since that is still important information for families.
- A working group member who could not be heard on the call noted agreement that the question regarding when a parent or professional should be concerned about ASD could be broadened to include milestones that should be monitored in order to detect delays in development. The LTSAE campaign at CDC was developed to educate parents and professionals on milestones in a variety of developmental domains, as well signs of delayed development, so children with ASD and other conditions can be connected to services as soon as possible. This approach to health education mirrors that of the AAP, Help Me Grow, the Administration on Children and Families, the Department of Education, and other organizations and is supported by parents in working group focus group discussions. This approach to health education also enhances detection of co-occurring conditions that may complicate and/or hinder the diagnosis of ASD.
- Members agreed to leave out language including diagnosis for adults, because that will be addressed in Question 6.
- The group decided to continue thinking about wording and circulate some options offline.

Title: When should I be concerned?

- Does the group want to consider making any changes to the chapter's title?

- Some members thought the question should be a "how" statement rather than a "when" statement. For example, how can we improve early detection and access to treatment and services?
- New title ideas mentioned included:
 - What should I look for and when?
 - What should concern me?
 - How early can ASD be identified?
 - How are kids getting detected early?
 - What should I do if I suspect my child had ASD?
 - How is ASD detected early and why is this so important?
 - What should I do if I'm concerned?
 - How would I know?
 - How would I know if I should be concerned?
- It was noted as a reminder that the title question is consumer-based and coming from the perspective of the family members of a child with ASD.

Wrap up and next steps

- Dr. Daniels and the co-chairs will begin preparing the chapter's narrative. Working group members are encouraged to volunteer to draft sections of the chapter.
- This was the final call for Question 1; all information will be circulated by email from now on.