# **IACC Strategic Plan Question 1 Outline**

## January 2017

Chapter Title: What are the signs of ASD and why is early detection so important?

<u>Aspirational Goal</u>: Provide the earliest possible diagnosis for children at risk for ASD, so they can be linked to appropriate interventions, services and supports in as timely a manner as possible to maximize positive outcomes.

#### I. Introduction

- Provide a general description of the issues covered in this question. You may refer to the previous version of the <u>Strategic Plan Q1 section</u> for guidance.
- II. For each of the following three sections, describe 1) what is known, 2) what are the gaps, barriers, and opportunities, 3) are there policy/services implications? If so, what are they?
  - \* Working group members agreed it might be beneficial to prepare the chapter topics 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.
    - Topic 1: Implementation of diagnostic and screening tools
      - Community settings without the assistance of researchers
      - Provider barriers and challenges
      - 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.

## • Topic 2: Disparities

- Access to early screening and diagnostic tools
- Culturally appropriate instruments

## • Topic 3: Workforce

- Increasing training and funding
- Preparing a culturally competent workforce

#### • Topic 4: Service System

- Greater collaboration among different sectors of service system to increase access for early screening and diagnosis
- Changes in ACA
- Impact of States Part C funding

Note: The issues of screening and diagnostic services, development of specific interventions such as alternative and augmentative communication technologies, adult diagnosis, transition services, employment, housing, and community integration will be covered in other Questions.

## III. Summary/Progress towards Aspirational Goal

### **New Objectives:**

- Objective 1: Strengthen the evidence base for the benefits of early detection of ASD.
  - i. Provide 3-5 examples of types of research and services that will be categorized to this objective:
    - 1. Suggestions:
      - 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;
      - To improve early detection there must be greater attention paid to special autism populations such as girls and intellectually delayed individuals.
- Objective 2: Reduce disparities in early detection by removing barriers to access and enhance culturally appropriate outreach efforts.
  - i. Provide 3-5 examples of types of research and services that will be categorized to this objective:
    - 1. Suggestions:
      - 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.
- Objective 3: Improve/validate existing, or develop new tools, methods, and service delivery
  models for detecting ASD that will facilitate timely linkage of individuals with ASD to early,
  targeted interventions and supports.
  - i. Provide 3-5 examples of types of research and services that will be categorized to this objective
    - 1. Suggestions:
    - It is important to address 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.