

**Summary of IACC Strategic Plan Working Group for Question 5 – Conference Call #3
November 1, 2016; 3:00pm ET**

Welcome and Introductions

Working Group Members in Attendance:

Shannon Haworth – Co-Chair
David Mandell – Co-Chair
Samantha Crane
Melissa Harris
Laura Kavanagh
Larry Wexler
Lauren Brookman-Frazee
Daniel Davis
Leticia Manning
Cathy Pratt
Anne Roux
Jane Tilly

Working Group Members Absent:

Brian Parnell
Robert Cimera
Peter Gerhardt
Lisa Goring
Aubyn Stahmer
Juliann Woods

Discussion of Chapter Outline

- Dr. Daniels mentioned that the Question 6 working group discussed the need for more evidence-based services research and increasing the portability of services across state lines. However, these topics seemed to align more with Question 5 research aims and therefore the Question 6 working group requested that the Question 5 working group address this issue during their third conference call.
- The Question 5 working group members discussed organizing the chapter topics by need rather than by type of research. The top needs would include: workforce, education & healthcare system, and lifelong supports.
- A few members were concerned if transition services, particularly transition to adulthood would be included in this chapter. Dr. Daniels clarified that transitions will be covered in Question 6.
- Disparities and access to services will be highlighted in this chapter.
- Under workforce needs, it was requested to highlight the need for provider training in crisis prevention.
- A member suggested to address in the chapter the need for appropriate services for those with co-occurring conditions, particularly mental health services.
- Working group members discussed the structural and policy barriers to coordinating providers to provide personalized services.
- There was a discussion on the need to assess quality control and quality accountability of services. Providing individuals with autism a range of options, under insurance or the school system, that

ensure individualization and choice. For example, a service policy issue that creates barriers to individualized and quality service occurs when regional centers send people to only a few select places or one kind of place for services. The individual may not be aware that there are other places to receive services or other types of services to seek.

Discussion of Proposed Strategic Plan Objectives for Question 5

Areas highlighted on previous calls for possible consideration:

1. Successful implementation of interventions and services in community settings.
 2. Broad dissemination of and access to evidence based-practices, including underserved populations
 3. Improved coordination of service systems
- The working group members agreed that the possible objectives 1 and 2 could be grouped together as one objective.
 - After combining objectives 1 and 2, another objective could be created focused on reducing disparities in access to services as well as reducing disparities in outcomes.
 - A third objective could deal with improving policy and coordination of service systems.
 - A working group member brought up that the NIMH Strategic Plan objectives and the Every Student Succeeds Act (ESSA) have language that could be useful for framing our objectives.
 - There was concern over using “evidence-based” language, that it would imply to policymakers and service providers a service must be evidence-based for it to be covered. There are some services that are not considered controversial and therefore have not been studied in the same way interventions have been (ex: caregiver respite). However, other working group members believed it is understood that not all services need to be evidence-based but that we do need to promote the ability to scale-up evidence-based services that are available. The group came to a decision that in the chapter’s narrative they will need to unpack the term “evidence-based practices” to describe fully what it means in regards to services and supports.
 - Several members addressed the need to include somewhere in the objectives the discovery of new service models. A suggestion was raised not to have objective 3 focus on coordination of services but instead to provide ways for more consistent and effective services and supports, such as developing and testing service models that are more effective at coordination, collaboration, transition, and adequate responsiveness.
 - A concern was raised to ensure we include in our wording the need for choice, accessibility, and focus on the individual.
 - Working group members decided the three objectives would have the main ideas below, but exact wording would be addressed further after some thought and research:
 - **Objective 1.** Fully and successfully scale up (evidence based?) interventions in community settings.
 - **Objective 2.** Reduce disparities in access and in outcomes for underserved populations.
 - **Objective 3.** Improving service models so that there is consistency of care across many domains with goal of maximizing outcomes and improving the value that individuals get from services.

Discussion of Change to Aspirational Goal and Chapter Title:

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 *and their families.*

1. On the last call, the group suggested adding the text in italics.
2. Also, does the working group want to further examine the word “necessary?” The Question 6 group is considering changing the word “necessary” in their aspirational goal to “appropriate” to avoid potential issues with determining what constitutes “necessary.” Or the word could be eliminated.

- Working group members confirmed the addition of “and their families” at the end of the aspirational goal.
- Members agreed to remove the word “necessary” but to keep “evidence-based” as long as it is explained in the narrative what evidence-based means to this group.
- Members decided to add the word “develop” to the beginning of the sentence.
- The sentence reads: **“Communities will develop, access, and implement high-quality, evidence-based services and supports that maximize quality of life and health across the lifespan for all people with ASD and their families.”**

Title of Chapter: Where can I turn for services?

- One member voiced concern that the way the title is phrased now makes it sound more like the IACC is providing resources.
- A revised version was suggested: “How can I find out which services are best?” However, members agreed they wanted to think about this more offline. Members agreed that it is important to keep in mind that the title should be phrased from the perspective of someone with autism or a family member.

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 the chapter topics they are interested in.
- This was the final call for Question 5; all information will be circulated by email from now on.