

**Summary of IACC Strategic Plan Working Group Question 6 – Conference Call #3  
November 1, 2016; 11:30am EDT**

**Welcome and Introductions**

Working Group Members in Attendance:

Brian Parnell – Co-Chair  
Julie Lounds Taylor – Co-Chair  
Samantha Crane  
Kevin Pelphrey  
Edlyn Peña  
Robyn Schulhof  
Scott Badesch  
Vanessa Hus Bal  
Somer Bishop  
Laura Klinger  
JaLynn Prince  
Susan White  
Denise Juliano-Built  
Robin Harwood

Working Group Members Absent:

Amy Goodman  
Leslie Caplan  
Nancy Cheak-Zamora  
Ophelia McLain  
Paul Shattuck  
Nancy Spencer

**Discussion of Chapter Outline**

- Working group members noted the need to make sure all topics discussed in Question 6 take into account the range of ASD, not just IQ and symptom severity, but socioeconomic differences, verbal compared to nonverbal, and sex differences.
- A working group member mentioned the need to address adult outcomes through long-term outcome studies; for example tracking the effect of an intervention from adolescence to adulthood.
- There was a discussion on separating out comorbidity and aging from health and healthcare, as well as separating physical health and health care from mental health and wellbeing.
- A working group member proposed the creation of a broad topic on legal issues. Currently, the issue of interactions with the criminal justice system is a subtopic under safety, but legal issues can be considered more cross-cutting if they cover more than criminal justice involvement – such as housing legal issues.
- It is important to address that while there is a coordinated effort of service delivery, we need to ensure that the services being delivered to adults with autism are effective and have a strong evidence base.

## Discussion of Proposed Strategic Plan Objectives for Question 6

Areas highlighted on previous calls for possible consideration:

1. Development and coordination of services to help youth make a successful transition to adulthood
2. Improvement of health, safety and well-being of individuals on the autism spectrum across the lifespan (can include issues like wandering, premature mortality, chronic health issues, comorbidities, adult diagnosis, the need for healthcare providers who are trained in addressing needs of people on the autism spectrum across the lifespan, etc.)
3. Increase acceptance, accommodation, inclusion, independence and integration of people on the autism spectrum (can address this in terms of employment, housing, recreational, social/relationship needs, development of better accommodations, etc.)
  - For the first possible objective, working group members agreed the objective's focus should be broader. It should acknowledge transitions throughout the adult lifespan. Examples mentioned included: aging and when a caregiver passes away.
  - Each objective can include examples of services or research needs. It was noted it is important to mention that research drives good services.
  - While treatments will be mainly addressed in Question 4 (Treatments & Interventions), this chapter can address the availability of appropriate interventions to sustain quality of life.
  - It was mentioned that these objectives should refer to the need for more medical research on adults with autism in order to answer: how are they aging, what are the underlying comorbidities (such as gut issues) amongst ASD adults, and, why is there premature mortality in this population.
  - Overall, the group liked the aims of the three proposed objectives, but with some slight wording adjustments.
  - Additional language for Objective 1 was suggested: **Support** development and coordination of **integrated** services to help youth make a successful transition to adulthood and **continue to provide additional supports throughout the lifespan.**
    - It was also suggested to remove "transition to adulthood" and instead have the phrase at the end "throughout the lifespan."
    - There was a suggestion to change it to "transitions throughout adulthood"
  - While the transition of caregivers has been highlighted as an area of focus, there is a particular need for an increase in research on service providers during this transition. This topic should be addressed under objective 3.
  - Working group members recommended the narrative of the chapter emphasize the importance of strengthening the evidence base and encouraging service providers to collect data on service participants' outcomes.
  - It was mentioned that it may be helpful to emphasize the need to better integrate funds for service delivery with funds for research.
  - Working group members cautioned that the "evidence base" terminology should be used carefully and be well-defined in the chapter; this will be addressed in the chapter on Question 5.
  - It was noted that the working group needs to coordinate with other chapters to ensure there is no overlap in topics but ensure that all areas are being addressed.

## Discussion of Aspirational Goal and Title

**All people with ASD will have the opportunity to lead self-determined lives in the community of their choice through school, work, community participation, meaningful relationships, and access to necessary and individualized services and supports.**

- The group discussed changing the word “necessary” to “appropriate.” Could also consider deleting the word.
- Working group members agreed to remove the word “necessary” and “individualized” from the aspirational goal.
- Some members believed language should be included such as: opportunity and access, at a reasonable cost, without undue waiting, equal opportunity, reasonable/meaningful access, without excessive burden. Members did agree that using the term “meaningful access” should be included in the aspirational goal.

**Title: “What does the future hold, particularly for Adults?”**

- Does the group want to consider changing the latter portion to be more inclusive of the whole lifespan? (i.e. “as individuals on the autism spectrum progress through the full lifespan?”)
- Working group members agreed they wanted to keep the term “adults” over using “lifespan” because this area is already underfunded and they do not want to dilute the issue.
- There was concern over using the terminology surrounding the “future.” It assumes it is parents of children who had this question, and instead the focus of the chapter will be adults with autism.
- The members decided to continue to think about the wording of the title and create some suggestions offline.

## Wrap up and next steps

- During the discussion a conversation arose about what government agencies are included on the IACC and if there is a possibility to request that more agencies participate. Dr. Daniels stated that only agencies named in the law are required to be part of the committee. However, the IACC can always ask an agency to come to the table when discussing a particular issue. In addition, the Secretary of Health & Human Services could request that an agency be added to the IACC
- An issue brought up by the working group was the portability of services between states; while this is not addressed in Question 6, it will be brought up to the co-chairs of Question 5 (Services).
- 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 5; all information will be circulated by email from now on.