

# IACC Strategic Plan Question 6 Outline

January 2017

**Chapter Title:** How can we meet the needs of people with ASD as they progress into and through adulthood (or across the lifespan)?

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

## I. Introduction

- General description on question's research area (see previous Strategic Plan Q6 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?

### ○ Topic 1: Transition to adulthood

- Healthcare
- Employment
- Education (secondary and post-secondary)
- social and community participation
- Mentioned in conference calls: Long-term outcome studies (ex: tracking effects of an intervention from adolescence to adulthood)

### ○ Topic 2: Health/healthcare

- Prevention
- mental health
- physical health
- aging
- co-occurring conditions
- Mentioned in conference calls:
  - Comorbidity
  - Aging
  - Physical Health
  - Mental Health
  - Healthcare needs
  - The need for more medical research on adults with autism in order to answer: how are they aging, what are the most pressing disabling symptoms and underlying comorbidities (such as gut issues) among ASD adults, and, why is there premature mortality in this population?

- **Topic 3: Supports for Vocational skills, Employment, Financial Planning**
  - Life skills supports and services
  - Research on effective tools for successful outcomes in vocational skills, employment, and financial planning
- **Topic 4: Community Integration**
  - Social and recreational opportunities
  - Housing
  - Inclusion
- **Topic 5: Safety**
  - Wandering
  - Self-harm
  - Criminal justice issues
  - Victimization
- **Topic 6: Adult diagnosis**
  - Benefits vs. harms
  - Would it be more beneficial if linked to adult services?
- **Topic 7: Long term supports, especially for high-needs individuals**
  - Research on effective long-term supports
  - Coordination of the service delivery system
  - 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.
- **Topic 8: Caregiver supports across the lifespan**
  - Increase in research on effective caregiver supports and caregiver transitions

### III. Summary/Overall Progress towards Aspirational Goal

#### New Objectives:

- **Objective 1: 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.**
  - Provide 3-5 examples of types of research and services that will be categorized to this objective:
- **Objective 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.)**

- Provide 3-5 examples of types of research and services that will be categorized to this objective:
- **Objective 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.)**
  - Provide 3-5 examples of types of research and services that will be categorized to this objective:
    - 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

\* *Within several of the above topics, consideration of:*

- Adult outcomes; developing quality of life and outcome measures that include the perspective of individuals on the autism spectrum; defining successful outcomes
- the range of ASD, not just IQ and symptom severity, but socioeconomic differences, verbal compared to nonverbal, and sex differences
- Personalized/individualized services
- Self-direction and autonomy, person-centered planning, choice
- Creating a supportive environment
- Coordination of care across service systems
- Assistance with navigation across service systems
- The role of technology in enabling access, independent living, etc.
- 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.