2016-2017 IACC Strategic Plan for Autism Spectrum Disorder

Outline of Question 5

In each of the topical sections below, discuss:

– What are the key research advances that have helped us make progress in the field?
– Are there areas of where research is ready to be moved into practice?
– Are there opportunities for practice to inform research?
– Are there any barriers to research in this area that need to be addressed?
  - In several of the topical areas, the working group said that research progress that has been made on understanding the existing barriers, but more research needed on how to address barriers
– What are the most pressing scientific questions, gaps, opportunities, and needs in this area?

– What are the most pressing services needs today? Are there any emerging needs?

- Workforce need that applies to multiple topics: Need for larger workforce to meet services needs; need more provider/practitioner training

- Service Systems: Need for further efforts to help families navigate the service system; efforts to ensure each individual's services are coordinated, recognizing that individuals are in multiple service systems

- Educational: Need for interventions to help keep children with disabilities in an instructional environment to maximize their potential

- Lifelong Supports: Need for communication supports, among other types of lifelong supports

- Is there new research evidence that can inform policy?

- What are the near-term and long-term ways that some of these services implementation and policy issues can be addressed? Through research or through policy changes?

Topics for Overview of Progress in the field:

1. Healthcare/Insurance Coverage

   • Interventions

   • Primary care

   • Health and safety, outcomes

   • Quality of services

   • Co-occurring conditions and severe autism – ensuring access to appropriate service

   • Coverage

- o Changes in ACA implementation, Medicaid
- o EPSDT as it relates to children receiving needed services (adult housing will be addressed in Q6)
- o Medical homes
- o Billing rates and reimbursement preventing implementation of evidence based practices (this also may apply in other topic areas)

- Economics research

  - o Could apply to multiple topic areas: More research is needed on economic outcomes and costs – need better data and better access to data to enable research

- Ensuring broad access

  - o Innovative strategies to enable access, such as telehealth – for providers and recipients of services

2. Education

- Quality of interventions

- Inclusion/participation

- Outcomes

- Distance learning

- Multiple diagnoses

- Implementation

  - o In education and other service areas, there is a need for more research on how to support providers so they can successfully implement evidence-based practices

  - o Also possibly applicable to several of the topic areas, there is a need to develop and build on current demonstration sites to provide infrastructure for implementation science and to determine how to best "scale up" successful models

3. Lifelong services and supports, including family supports

- Communication supports

- Caregiver supports

- Outcomes and quality of services

- Person centered planning and self-direction

4. Coordination of care across service systems

5. Disparities

- Underserved populations within the ASD community (ethnic, racial, cultural, gender, etc.)

- Recognition of disabled individuals as an underserved population in various services systems – some organizations are recognizing disabled individuals as underserved and in need of targeted strategies to reduce disparities in service access, etc.

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

- **Progress Toward the Question's Aspirational Goal**

  Question 5 Aspirational goal: 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]. (New addition suggested by this working group.) Additional suggestions will be considered on conference call #3.

  – The group discussed this aspirational goal and agreed it is still an appropriate long-term goal for this area, with the addition of families at the end of the goal. Wil need a paragraph affirming that the committee still feels this is an appropriate goal, perhaps citing some ways in which we are reaching toward it, but acknowledging that there are many opportunities to continue moving in this direction in the future.