



## **Member Feedback on the IACC Strategic Plan**

### Summary

April 13-14, 2022

**Revised Strategic Plan Title**

| <b>Proposed Title</b>   | <b>Number of Votes</b> |
|---|------------------------|
| IACC Strategic Plan for Autism Research, Services, and Policy | 28                     |
| IACC Strategic Plan for Autism Spectrum Disorder              | 6                      |
| Other   | 3                      |

*Note: Since the enactment of the Autism CARES Act of 2014, the IACC Strategic Plan has been required to address issues related to services and supports, as well as research.*

**General Comments**

- Increased need for inclusion in research, including community-based participatory research
- Addressing disparities
- Address the whole spectrum and the whole lifespan
- Emphasize actions and solutions where possible
- Emphasize commitment to equity and inclusion and elimination of stigma and discrimination
- Language considerations
  - Move away from deficits-based language and toward more neutral, strengths-based, or inclusive language when describing autism
  - Maintain accuracy when referring to issues that may be medical or clinical in nature

**Important Topics to Address**

***Question 1: Screening and Diagnosis***

- Biomarkers
- Universal screening
- Availability of and access to services
- Disparities
- Detection and intervention before behavioral differences are apparent
- Telehealth approaches
- Tools (e.g. milestone tracking)
- Translating research findings into practice
- Medical practitioner training
- Caregiver engagement
- Systems navigation

***Question 2: Biology***

- Sensory and motor differences
- Co-occurring physical and mental health conditions
- Cognition and behavior
- Brain function and connectivity
- Human neuroimaging studies
- Sex differences; female protective effect

- Longitudinal studies
- Translational studies
- Microbiome
- Biology across the lifespan
- Ethics of human studies

**Question 3: Genetic and Environmental Factors**

- Interactions among multiple genetic, epigenetic, and/or environmental factors
- Large genetic and epigenetic studies
- Diversity in genetic studies
- Subtypes of genetic variants
- Shared factors impacting autism and co-occurring conditions
- Modifiable environmental factors (e.g. maternal diet)
- Influence of genetic factors on response to medications

**Question 4: Interventions**

- Medical, behavioral, educational, and complementary approaches
- Interventions that improve quality of life
- Interventions for co-occurring physical and mental health conditions?
- Personalized, culturally-competent interventions
- Naturalistic Developmental Behavioral Interventions (NDBIs)
- Pre-emptive intervention for challenging behaviors
- Parent/caregiver-mediated interventions
- Communication tools, alternative and augmentative communication (AAC)
- Outcome measures and biomarkers
- Community access to information about safety and efficacy
- Telehealth approaches
- Technology-based interventions

**Question 5: Services and Supports**

- Scaling and implementing interventions
- Health system integration
- Community-based service delivery
- Identifying and reducing disparities
- Family dynamics, support, and engagement; parent and sibling perspectives
- Workforce training and development
- Person-centered services
- Systems navigation
- Medicaid, Medicare, and Social Security policies

**Question 6: Lifespan**

- Adult diagnosis
- Transition outcomes
- Social determinants of health, including:
  - Employment
  - Housing
  - Safety
  - Family dynamics and trauma

- Community inclusion
- Aging autistic adults

#### ***Question 7: Infrastructure and Surveillance***

- Improvement and expansion of systems that track autism prevalence
- Public-private partnerships
- Data banks and biobanks
- Privacy guidelines
- Adult prevalence studies
- Community outreach/dissemination of information
- Research and clinical workforce development
- Support for early career researchers

#### ***COVID-19 Pandemic***

- Mitigating increased risk of COVID-19 in autistic individuals
- Effect of disruptions in school, access to intervention/services
- Mental health supports
- Impact of switch to remote school, work, healthcare, and services
- Impact of the pandemic on research community

#### ***Disparities***

- Reduce disparities in diagnosis, access to services and supports
  - Race/ethnicity
  - Gender
  - Sexual orientation/gender identity
  - Disability status
  - Socioeconomic status
  - Geographical location
- Increase inclusion and engagement with underserved communities
- Increase diversity in research and clinical workforce
- Increase cultural competency of educators, medical practitioners, and other service providers