Member Feedback on the IACC Strategic Plan

Summary

April 13-14, 2022
Revised Strategic Plan Title

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<th>Proposed Title</th>
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<td>IACC Strategic Plan for Autism Research, Services, and Policy</td>
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<td>IACC Strategic Plan for Autism Spectrum Disorder</td>
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<td>Other</td>
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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