Draft IACC Strategic Plan Question Titles, Aspirational Goals, and Objectives January 2017

Question 1

Title: What Are the Signs of ASD and Why Is Early Detection So Important?

Aspirational Goal: Provide the earliest possible diagnosis for children and adults on the autism spectrum, so they can be linked to appropriate interventions, services, and supports in as timely a manner as possible to maximize positive outcomes.

Objectives:

- 1. Strengthen the evidence base for the benefits of early detection of ASD.
- **2.** Reduce disparities in early detection by removing barriers to access and enhance culturally appropriate outreach efforts.
- 3. Improve/validate existing, or develop new tools, methods and service delivery models for detecting ASD that will facilitate timely linkage of individuals with ASD to early, targeted interventions and supports.

Question 2

Title: What Is the Biology Underlying ASD?

Aspirational Goal: Discover how alterations in brain development and nervous system function lead to ASD in order to enable the development of effective, targeted interventions and societal accommodations that improve quality of life for people on the autism spectrum.

Objectives:

- **1.** Foster research to better understand the genetic and non-genetic components that contribute to the structural and functional basis of ASD.
- **2.** Support research to understand the underlying biology of co-occurring conditions in ASD and to understand the relationship of these conditions to ASD.
- **3.** Support large scale longitudinal studies that can answer questions about the development of ASD from pregnancy through adulthood and the natural history of ASD across the lifespan.

Question 3

Title: What Causes ASD, and Can Disabling Aspects of ASD be Prevented or Preempted?

Aspirational Goal: Causes of ASD will be discovered that inform diagnosis, prognosis, and treatments and lead to prevention/preemption of the challenges and disabilities of ASD.

Objectives:

- 1. Strengthen understanding of genetic risk factors for ASD across a large population representing the full diversity and heterogeneity of those with ASD, enabling development of strategies for reducing disability and comorbidities in ASD.
- 2. Understand the effects on ASD risk of individual and multiple exposures in early development, enabling development of strategies for reducing disability and comorbidities in ASD.
- **3.** Expand knowledge about how multiple environmental and genetic risk factors interact through specific biological mechanisms to manifest in ASD phenotypes.

Question 4

Title: Which Treatments and Interventions Will Help?

Aspirational Goal: Develop a range of interventions that optimize function and abilities across the lifespan to achieve meaningful outcomes and maximize quality of life for people on the autism spectrum.

Objectives:

- **1.** Develop and improve pharmacological and medical interventions to address both core symptoms and comorbidities in ASD.
- **2.** Develop and improve cognitive, behavioral, social, developmental, and naturalistic interventinos for ASD.
- **3.** Maximize the potential for technologies and development of technology-based interventions to improve the lives of people on the autism spectrum.

Cross cutting themes applicable to all three objectives:

- 1. Enhance understanding of the brain basis and mechanisms underlying these therapeutic approaches.
- 2. Maximize effectiveness (efficacy? benefits?) for individuals taking advantage of combination therapies.
- 3. Develop more robust standardized outcome measures, including adaptive measures, predictive measures, measures that address heterogeneity, and measures of practical outcomes that will help better target therapies to individual needs.
- 4. Ensure support for the entire intervention research and development pipeline.
- 5. Support translation of research to community-based practice and use of effective dissemination strategies to maximize uptake of evidence-based practice.

Question 5

Title: What Kinds of Services and Supports are Needed [to Maximize Quality of Life] [for People on the Autism Spectrum]?

Aspirational Goal: Communities will develop, access, and implement 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.

Objectives:

- 1. Fully and successfully scale up evidence-based interventions in community settings.
- 2. Reduce disparities in access and in outcomes for underserved populations.
- **3.** Improve service models to ensure consistency of care across many domains with the goal of maximizing outcomes and improving the value that individuals get from services.

Question 6

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.

Objectives:

- **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.
- 2. Improve health, safety, and well-being of individuals on the autism spectrum across the lifespan.
- **3.** Increase acceptance, accommodation, inclusion, independence, and integration of people on the autism spectrum.

Question 7

Title: How Do We Continue to Build, Expand, and Enhance the Infrastructure System to Meet the Needs of the ASD Community?

Aspirational Goal: Develop, enhance, and support infrastructure and surveillance systems that advance the speed, efficacy, and dissemination of ASD research and services.

Objectives:

- **1.** Promote growth and integration of the biorepository infrastructure.
- **2.** Develop, enhance, and link the data infrastructure.
- **3.** Develop the human infrastructure to disseminate research, support community-based service delivery, and communicate science.