2016-2017 IACC Strategic Plan for Autism Spectrum Disorder

Question 7 (What Other Infrastructure and Surveillance Needs Must be Met?) Outline

- Develop the Biorepository Infrastructure
  - Support brain banking (Autism BrainNet, National Institutes of Health NeuroBioBank)
  - Support fibroblast, blood, saliva, and other tissue collection (National Institute of Mental Health (NIMH) Repository and Genomics Resource, Autism Genetic Resource Exchange (AGRE))

- Develop the Data Infrastructure
  - Surveillance
    - Autism and Developmental Disabilities Monitoring (ADDM) Network, early ADDM, South Carolina's Children's Educational Surveillance Study (SUCCESS), efforts to understand prevalence in adults
  - Data Banks (for purpose of data sharing)
    - National Database for Autism Research (NDAR)
    - Genetics/genomics data banks, and the need for stronger efforts to avoid resequencing the same individuals by more strongly encouraging data sharing and the use of GUIDs
  - Ability to build virtual cohorts, and the use of technology (apps and devices) and surveys to collect data
    - Interactive Autism Network (IAN)
    - National Survey of Children's Health
    - National Health Interview Survey
    - Standardization of measures to enhance sharing

- Develop the Human Infrastructure to Support Research and Service Delivery
  - Research training and workforce development efforts
  - Foster collaboration between researchers in the U.S. and globally
  - Dissemination of science, including use of technology to enhance dissemination (apps)
  - Efforts to educate the public about autism services and best practices
  - Efforts to educate the public about the importance of research participation