

IACC Strategic Plan Question 7 Outline

January 2017

Chapter 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.

I. Introduction

- General description on question's research area – You may refer to the description provided in the previous version of the Strategic Plan and revise if you wish
<https://iacc.hhs.gov/publications/strategic-plan/2013/#q7>

II. For each of the following three sections, describe 1) what is known or what activities are current, 2) what are the needs, gaps, barriers, and opportunities, 3) what are the policy/services implications, impact for the community?

- **Topic 1: Biorepository Infrastructure (Michelle Freund)**
 - i. Support brain banking (coordination of efforts between the Autism BrainNet, National Institutes of Health NeuroBioBank)
 - ii. Support fibroblast, blood, saliva, and other tissue collection (National Institute of Mental Health (NIMH) Repository and Genomics Resource, Autism Genetic Resource Exchange (AGRE))
 - iii. Efforts to encourage donation and participation in research
- **Topic 2: Data Infrastructure (Maureen Durkin, Catherine Rice, Daisy Christensen, Dan Hall, Gretchen Navidi, Adriana DiMartino, Paul Lipkin, Jessica Rast)**
 - i. Surveillance
 1. Autism and Developmental Disabilities Monitoring (ADDM) Network, early ADDM, National Survey of Children's Health, National Health Interview Survey (NHIS), South Carolina's Children's Educational Surveillance Study (SUCCESS), efforts to understand prevalence in adults
 - ii. Data Banks (for purpose of data sharing)
 1. National Database for Autism Research (NDAR)
 2. 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
 - iii. Ability to build virtual cohorts, and the use of technology (apps and devices) and surveys to collect data
 1. Interactive Autism Network (IAN)
 2. National Survey of Children's Health
 3. National Health Interview Survey
 4. Ensuring that data collected through small registries and projects are integrated into the data network

- 5. Standardization of measures to enhance sharing
- iv. Accessibility of data sets to biomedical and services researchers
- v. Challenges of data sharing: many researchers feel uncomfortable sharing data and feel a need to protect their scientific productivity; however, data should still be shared promptly and timely within the research community
- vi. Expanding upon existing databases
- **Topic 3: Human Infrastructure (Andy Shih, Michael Rosanoff)**
 - i. Research training and workforce development efforts
 - 1. Opportunities for trainees and young investigators to do secondary data analysis using large data sets
 - ii. Foster collaboration between researchers in the U.S. and globally
 - iii. Dissemination of science, including use of technology to enhance dissemination (apps)
 - 1. Highlight the dissemination of research separately from the dissemination of services
 - iv. Efforts to educate the public about autism services and best practices
 - v. Efforts to educate the public about the importance of research participation

III. Summary/Progress towards Aspirational Goal

IV. New Objectives

- **Objective 1: Promote growth and integration of the biorepository infrastructure.**
 - i. If you wish, you may provide 3-5 examples of research/services areas or needs that you would like to see addressed by projects related to this objective
- **Objective 2: Develop, enhance, and link the data infrastructure.**
 - i. If you wish, you may provide 3-5 examples of research/services areas or needs that you would like to see addressed by projects related to this objective
- **Objective 3: Develop the human infrastructure to disseminate research, support community-based service delivery, and communicate science.**
 - i. If you wish, you may provide 3-5 examples of research/services areas or needs that you would like to see addressed by projects related to this objective