

Summary of Working Group 7 – Conference Call #3

November 2, 2016; 11:00 am EDT

Welcome and Introductions

Working Group Members in Attendance:

Alison Singer – Chair
Daisy Christensen
Dan Hall
Gretchen Navidi
Jessica Rast
Michael Rosanoff
Adriana DiMartino
Michelle Freund
Catherine Rice

Working Group Members Absent:

Robert Ring
David Mandell
Paul Lipkin
Robin Harwood
Samantha Crane
Maureen Durkin
Andy Shih

Discussion of Chapter Outline

- A working group member suggested to the group a cross-cutting category for the three individual outline categories (1. Develop the Biorepository Structure, 2. Develop the Data Infrastructure, 3. Develop the Human Infrastructure for Research and Services). This cross-cutting category promotes linkage between autism registries in order to avoid both resequencing of individuals involved in research and duplication of effort.
- Data sharing was described as still having many challenges, particularly in the National Database for Autism Research (NDAR). A group member shared that 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. While NDAR does have data sharing guidelines in place to promote timely data sharing, there can be more efforts implemented to enforce or encourage researchers to share data sooner. There needs to be more monitoring of policies dictating data sharing so that data are not kept private for too long.
- Based on the outline structure, a member requested the National Survey of Children’s Health and National Health Interview Survey be included under the surveillance section of the chapter narrative. These surveys are used with surveillance tools to provide information to policymakers and stakeholders.

Discussion of Strategic Plan Objectives for Question 7

Areas highlighted on previous calls for possible consideration:

1. Develop the Biorepository Structure
2. Develop the Data Infrastructure
3. Develop the Human Infrastructure for Research and Services

General comments

- Several working group members expressed the view that the infrastructure described in Question 7 has already been developed and now needs to be integrated. In contrast to the working group members who believe that the infrastructure has already been developed, it was stated that the audience of this report includes Congress. Therefore, if Congress reads that the infrastructure has already been built, they may think that there is no longer a need to provide funding for this area. To resolve this disagreement over the appropriate terminology for the objective, a working group member recommended that the objectives should be specific in terms of what still needs to be done. Instead of using the word “develop,” it was recommended that other words be used such as: “extend”, “leverage”, “promote”, “enhance”, or “integrate.”
- The working group was also reminded to keep the objectives broad but use specific examples.

Three Proposed Objectives for Question 7:

1. Develop the Biorepository Structure

- Several working group members maintained that since the biorepository structure already exists, “develop” is not an appropriate word to use. These members suggested replacing “develop” with “integrate”, “promote growth”, “promote additional development,” or “improvement/enhancement”. However, another member expressed concern about eliminating the word “develop”, stating that if it appears from the language that the infrastructure or biorepositories are complete, then it may be difficult to get continued funding. Specific examples of work still needed on the biorepositories are: the need for more population and distribution of biological tissue.
- A recommended revision of the objective is: Promote growth and integration of the biorepository infrastructure.

2. Develop the Data Infrastructure

- Working group members again voiced the need to change the language of “develop” to “enhance,” “linking,” or “building” since they believe that the data infrastructure is already established. The focus should be more on standardization of collection, data measures, and service delivery.
- The Autism and Developmental Disabilities Monitoring (ADDM) Network and the National Database for Autism Research (NDAR) were highlighted as examples of well-developed functional databases that must continue to expand. It was stated that NDAR could continue to work to link all autism databases.

- While linking and enhancing existing databases is a main goal, it is important to develop different database structures so that it can provide different information.
- A recommended revision of the objective is: Develop, enhance, and link the data infrastructure.

3. **Develop the Human Infrastructure for Research and Services**

- It was proposed that the third objective needs to call attention to the dissemination of science. This objective should also make mention of training researchers to advocate for themselves, and researchers should be taking part in enhancing the dissemination of their findings. Building the science of communication will improve effectiveness of the strategic plan message.
- It was suggested the phrase “dissemination of research” should be added to the third objective.
- A working group member maintained that research infrastructure and service infrastructure need to be considered separately.
- A recommended revision of the objective is: Develop the human infrastructure to disseminate research, support community-based service delivery, and communicate science.

Discussion of Aspirational Goal and Title:

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

The group discussed adding the text in italics.

- In addition to adding the text “and services,” the working group decided to add the text “enhance” to the Aspirational Goal so that it now reads: “Develop, **enhance**, and support infrastructure and surveillance systems that advance the speed, efficacy, and dissemination of ASD research **and services.**”

Title: What Other Infrastructure and Surveillance Needs Must Be Met?

The group proposed: “How do we leverage the infrastructure system to meet the needs of the ASD community?”

Does the group want to accept this suggestion?

- The working group decided that the term “leverage” implies an already completed process, so the members decided to use the text: “build, expand, and enhance” so that the new question reads: “How do we continue to build, expand, and enhance the infrastructure system to meet the needs of the ASD community?”

Wrap up and next steps

- Dr. Susan Daniels will be in contact with the working group chair, Alison Singer, to create a plan for drafting Chapter 7.
- The working group members will be contacted regarding specific sections that need to be written. The members should let Dr. Susan Daniels and Alison Singer know if there is a specific section any of them have an interest in writing.
- A draft of Chapter 7 is planned to be prepared by the next IACC meeting on January 13, 2017.