

Draft Working Group 7 – Conference Call #2 Summary
October 6, 2016; 10:30 am EDT

Welcome and Introductions

Working Group Members in Attendance:

Alison Singer – Chair

Daisy Christensen

Dan Hall

Robert Ring

Paul Lipkin

Gretchen Navidi

Jessica Rast

Michael Rosanoff

Romi Azuine (for Robin Harwood)

Working Group Members Absent:

Samantha Crane

Maureen Durkin

Andy Shih

Adriana DiMartino

Michelle Freund

Catherine Rice

Follow-up, Call 1

- OARC followed up with Autism Speaks after the first conference call to assess if all of Autism Speaks projects were included and coded correctly. After reviewing Autism Speaks portfolio, all projects were confirmed to be included and coded correctly.

Discussion of Public Comments received through Request for Information

- The working group members considered the public comments to be in-line with current autism research initiatives that are being funded.
- One working group member noted the call for stronger adult services, but with a focus on the infrastructure needed to think of services as an age continuum. Many parents express difficulty with all age transitions. While much of this research will be categorized in Question 6 (Lifespan Issues), the discussion could influence some of the research and policy addressed in Question 7 (Surveillance & Infrastructure).

Discussion of Progress, Needs, Gaps, and Opportunities

Discussion Questions:

1. What are the most notable areas of recent progress in with regard to research infrastructure? What new opportunities have emerged?
 - The working group members agreed that infrastructure for autism research falls into three possible divisions:

- a. Human infrastructure, which focuses on research training and workforce development, as well as public education and collaboration.
 - b. Data infrastructure, which addresses surveillance, access to databases and datasets, data sharing policies. Examples of current databases include: the National Database for Autism Research (NDAR), the Autism Genetic Resource Exchange (AGRE), and the Interactive Autism Network (IAN).
 - c. Bio repository infrastructure, which addresses the needs of biobanks, such as those collecting and storing brain, fibroblasts, blood, and saliva samples. Examples of current biorepositories included: Autism Brain Net, the National Institutes of Health (NIH) NeuroBioBank, the Autism Tissue Program, and the National Institute of Mental Health (NIMH) Repository and Genomics Resource.
- Members of the working group discussed how communities of parents of children with autism have been developing grassroots autism patient registries to improve readiness for clinical trial use. While some members noted that the infrastructure does exist to include the collected data in existing data networks, it is important to address in the next Strategic Plan the linking mechanisms and protocol standardization needed to include these small data collections in the larger network.
 - Recently, the use of national surveys has been beneficial in the research progress surrounding the prevalence and surveillance of ASD. Surveys such as the National Survey of Children’s Health and the National Health Interview Study are available online, making it easily accessible for researchers to attain and perform secondary statistical analyses.
2. Are there any innovative programs or recent policy changes that have advanced the field?
- NDAR includes NIH’s research data and has already made progress federating data with Simons Foundation, IAN, and AGRE. These agreements have been beneficial, and these efforts should be expanded.
 - The NIH grant review process evaluates every grant for data sharing option that are offered, which makes sharing data a necessity.
 - As stated by a working group member, Johns Hopkins University is already providing technical support of data analysis to people without data expertise in order to make databanks more accessible.
3. What are the most pressing needs or evidence gaps that can be addressed through creation and support of research infrastructure? Opportunities to build onto existing infrastructure?
- While there are several national surveys that included autism questions, there are many more existing national surveys that do not include information on autism but could add autism questions to gather more data.
 - It was proposed in the working group that national surveys can and need to be connected to other databases.
 - While several agencies include any data collected on their websites for researchers to use, many surveys and datasets require more effort to access the data, such as: difficulty finding where the data is housed, trouble finding who the contact person is, and lengthy procedures to establish access to the data. Access to statistical programs are also sometimes required for the analysis of

the data. Databases focused on services and education data are often not harmonized or well-known to many researchers. Also, retrospective data sharing can be very difficult and expensive. It would be beneficial to researchers in this area to have a place to harmonize and promote the datasets.

- Our surveillance studies need to include ways to capture the spectrum of impairment. It would be beneficial to review studies from the UK that focus on this, particularly for adult prevalence.
- According to working group members, more should be done to capitalize on the investment that went into collecting existing large datasets, which provide opportunities for junior investigators and graduate level students to receive training in secondary data analyses.

4. What are the most significant barriers to progress, and can we address them?

- The IACC Strategic Plan for Autism Research Question 3: *What Causes Autism?* Research in environmental risk factors is a major component in the response to this question, and objectives address the need for research on: While there has been progress in the coordination of biobanks, it remains a challenge to get people to register and donate tissue. The field has not recovered from the loss of tissue samples from one of the biobanks. There is a lack of public awareness and understanding, and it is necessary to educate families and individuals with ASD about the importance of participating in research, so that more studies can include a sufficient number of subjects.
- Member of the working group advised that research should examine what factors are keeping individuals and families from participating in studies. Parents may encounter barriers even though they want to participate. Some possible barriers may be: travel fare and child care for other children. Younger parents seem to show an interest in smartphone technologies and other technology for participation, though security and privacy issues need to be considered. Research needs to examine new modalities for accumulation of child participants.
- Another barrier to participation in research is that families do not understand all the restrictions to research participation. For example, if a Vineland diagnosis was done at Yale for one study, why does the family have to do a Vineland again at NYU for another study? Some working group members suggested that if someone receives a Vineland diagnosis in one year it should be eligible for any studies they participate in that year. Overall, it would be beneficial for the research community to standardize the research requirements for inclusion in certain studies and catalog eligible participants for other studies to use.
- An observed problem shared by a working group member is that questions between different surveys have not always been comparable due to the use of different terminology and diagnostic criteria. An example of this problem has been that some studies ask about current diagnosis while others ask about historical diagnosis. It was mentioned that a recent paper discussed how the order and wording of questions can affect the results of prevalence surveys. Therefore, the lack of standardized surveys is creating a barrier.
- Working group members discussed the multiple sources of data across agencies and noted that the data is not well harmonized, creating a large amount of inefficiency that needs to be tackled and addressed.
- There are challenges to a larger world of federation. We need to address the policies defining data sharing and standardization of protocols and collection so that we can reduce the barriers

to data access in the long term. An example that was mentioned is including informed consent in an appropriate, yet broad way.

- There was agreement in the working group that there needs to be more workforce training, specifically for the medical workforce. While there is progress in early identification, there is an absence of adequate medical professionals trained to identify the early signs of ASD. Also, there is a lack of medical professionals that are knowledgeable in addressing the needs of adults with ASD. More funding has been provided to train child neurologists in the research field, although not specifically in the ASD research field.
- According to working group members, there are not enough services readily available for those in the age range of 18-21 with ASD to find health care.

5. What progress has been made in ASD surveillance?

- The Autism and Developmental Disabilities Monitoring (ADDM) Network will have new state-based prevalence estimates, and will simultaneously produce prevalence rates from DSM-4 and DSM-5, in part to investigate the differences between these data. The program also is looking at the intersection of data collection from the ADDM network and national surveys as well as other ways of collecting surveillance data on ASD. The ADDM Network is also hoping to expand its efforts to look at prevalence in other age groups of children (beyond 8-year-olds).
- South Carolina's Children's Educational Surveillance Study (SUCCESS) is underway. However, it has not produced any recent publications. The working group members suggested reaching out to the investigators to see if they may be willing to share their preliminary findings.

6. What are the most pressing surveillance needs and opportunities, and how can we address them?

- Members of the working group agreed that there is an urgent need to establish prevalence rates for adults with autism. A member explained that the ADDM network is not equipped to address this issue, although it could be helpful to link previous ADDM results to other databases that would provide information on services for transition to adulthood. A working group member stated that a true prevalence rate of adults with autism is a major undertaking. This should be kept in mind for future priorities on adults. A few working group members expressed problems with lack of experts with statistical expertise and survey-specific expertise. While some researchers may have general statistical knowledge, the surveys often contain complex sampling designs that require advanced training in the procedures. Along those lines, many databases charge researchers to have access to their data or documentation files.

7. How can we support increased dissemination of research/evidence- based practices?

- The public is interested in the latest research findings as well as participant-level data; however, there has been a gap in communicating information to families. Either families do not know the places to review this information or if they find information it is often not translated in terms for families to understand. There is a large amount of funding, from both public and private organizations, going into autism research initiatives. It is important to develop guidance and priorities around standardizing a framework to establish commercial products that disseminate findings to families in a format that is appropriate. The development of an app-based approach

was suggested. To build public trust, funders need to effectively communicate the benefits resulting from autism research.

- It was noted by a working group member that the Federal policies governing data have influenced the access to data and made access too limited. Allowing more access to data sets will improve the analysis and allow for the dissemination of best practices.
- The working group members suggested that data in NDAR should be associated with the publications that arise from it.

8. How can we better support US and international collaboration?

- The working group members discussed new emerging opportunities for research in the U.S. to collaborate with the international community. It was stated that collaboration with international research will create an increased need to standardize data sharing and measurement.
- While there has been an increase in ASD research publications outside of the U.S. and other developed countries who often led the research field, there is still an imbalance in the number of researchers in other parts of the world. There is an opportunity to enhance the work we are doing through partnerships at the community and government level of other countries. It will be helpful to learn more about what ASD looks like in international populations, as well as the community-based strategies employed in other countries to increase access to services and awareness.
- The U.S. must also disseminate ASD findings, best practices, and awareness to low-resourced countries.
- Within the U.S., there is a need for more service system collaboration, such as between the Social Security, education/vocation, and support systems. The long-term goal is to combine data from multiple services interactions for a single individual.

Discussion of Aspirational Goal

Based on the state of the field, is the **Question 7 Aspirational Goal** still appropriate?

“Develop and support infrastructure and surveillance systems that advance the speed, efficacy and dissemination of ASD research.”

- The working group decided that the aspirational goal should also include language about services. Members agreed to add at the end of the sentence, “...ASD research **and services.**”

“What Other Infrastructure and Surveillance Needs Must Be Met?”

- The working group members stated that since there is infrastructure and surveillance in place, the question is how to leverage the infrastructure to meet the needs of the autism community, including people on spectrum, and their families.
- Working group members suggested, “How do we leverage the infrastructure system to meet the needs of the ASD community?” However, members have not decided on a final revision on the chapter title.

Wrap up and preview of next call

- Susan Daniels will be working with the working group Chair, Alison Singer, to prepare an outline of Chapter 7. The goal is to complete it by December.
- The next Working Group 7 conference call will discuss the development of objectives that address the priority of needs in surveillance and research infrastructure.