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INTERAGENCY AUTISM COORDINATING COMMITTEE

SUBCOMMITTEE FOR

BASIC AND TRANSLATIONAL RESEARCH

STRATEGIC PLAN QUESTION 7 PLANNING GROUP

CONFERENCE CALL

FRIDAY, NOVEMBER 8, 2013

The Strategic Plan Question 7 Planning Group convened via conference call at 10:30 a.m., Susan Daniels, Executive Secretary, IACC, presiding.

PARTICIPANTS:

THOMAS INSEL, M.D., *Chair*, IACC, National Institute of Mental Health (NIMH)

SUSAN DANIELS, Ph.D., *Executive Secretary*, IACC, Office of Autism Research Coordination (OARC), (NIMH)

STAN NIU, Ph.D., U.S. Department of Defense (representing Donna Kimbark, Ph.D.)

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ALISON SINGER, M.B.A., Autism Science Foundation (ASF)

EXTERNAL PARTICIPANTS:

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MAUREEN DURKIN, Dr.P.H., M.P.H., University of Wisconsin-Madison

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PAUL LAW, M.D., M.P.H., Kennedy Krieger Institute

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PROCEEDINGS:

Operator: Welcome, and thank you for standing by. All participants will be listen-only throughout the duration of the conference. This conference is being recorded. If anyone has any objections, you may disconnect at this time.

I will now turn the call over to Dr. Susan Daniels. You may begin.

Dr. Susan Daniels: Good morning. Thank you for joining us for this Question 7 Planning Group conference call for the IACC.

This morning we have a number of invited experts with the IACC members to have a discussion about Question 7 of the Strategic Plan. I'd like to go through the roll call just so people know who's on the phone.

So, Dr. Tom Insel? Are you here?

Dr. Thomas Insel: I'm here. Thanks, Susan.

Dr. Susan Daniels: Alison Singer?

Ms. Alison Singer: I'm here.

Dr. Susan Daniels: Thanks.

Stan Niu for Dr. Kimbark?

Dr. Stan Niu: I'm here.

Dr. Susan Daniels: Thank you.

Cathy Rice is going to be joining at 11 o'clock from CDC.

Dan Hall?

Mr. Dan Hall: I am here.

Dr. Susan Daniels: Thanks.

Julie Daniels?

Dr. Julie Daniels: I'm here.

Dr. Susan Daniels: Thank you.

Maureen Durkin?

Dr. Maureen Durkin: Yes, I'm here.

Dr. Susan Daniels: And Paul Law? Maybe he'll be joining us later.

And Thomas Lehner is also part of this Group, from NIMH, but he's on travel and can't make it to the call today.

So I'd like to take a couple of minutes just to have each of the invited participants introduce themselves and just very briefly to tell us what institution or organization you're from and what you work on.

So, Dan Hall?

Mr. Hall: Yes. I am a contractor, and I have the role of manager of the National Database for Autism Research, which is a role I've served for 6 years. And I should also note that I am the father of a 17-year-old minimally verbal son.

Dr. Susan Daniels: Thank you.

Dr. Julie Daniels, can you give us a couple of lines to introduce yourself?

Dr. Julie Daniels: Sure. I'm at The University of North Carolina, and I'm in the Departments of Maternal and Child Health and Epidemiology. And I primarily look at research that looks at exposures during pregnancy that might be related to autism. I'm the PI of one of the ADDM sites on [Inaudible] CDC, which conducts surveillance for autism and the PI of a site for the SEED study, which is also a CDC-supported study to look at causes and correlates of autism.

Dr. Susan Daniels: Great, thank you.

Maureen Durkin, can you introduce yourself?

Dr. Durkin: Yes. I am an epidemiologist also and professor of population health sciences and pediatrics at the University of Wisconsin-Madison. I'm also at the Waisman Center there, which is a research study devoted to developmental disabilities. And I am also the PI for the ADDM site here in Wisconsin.

Dr. Susan Daniels: Thank you.

Paul Law, have you joined yet?

Paul Law is from the Kennedy Krieger Center, and he is going to, hopefully, be joining us later.

And we do also have one other person who's new on the call, Stan Niu, who's in for Donna Kimbark.

Stan, could you introduce yourself?

Dr. Niu: Sure. My name is Stan. I'm the Science Officer at the Congressionally Directed Medical Research Programs. I'm on the team with Donna Kimbark for the autism research programs. Donna -- she has some family matters, so she cannot attend this meeting. So I am covering for her.

Dr. Susan Daniels: Thank you.

Cathy Rice will be joining us later. And I don't know, Tom Insel or Alison Singer, if you'd like to introduce yourselves, or if you'd like to just move forward.

Dr. Susan Daniels: I think everybody probably is pretty familiar with some of our veterans, who have been on pretty much every call of the IACC since –

[Inaudible comment]

Dr. Insel: Susan, this is Tom.

Dr. Susan Daniels: Yes.

Dr. Insel: One thing I do need to say is that I'm in the neuroscience meeting in San Diego. So I have to leave at -- well, in about 30 minutes to go into a session where I need to be – so time is pretty limited.

Dr. Susan Daniels: Okay. Thank you. Thank you very much. And we realize the Society for Neuroscience is going on right now, and so there were people that weren't going to be able to listen in on the call or join, although our members are here.

So on today's call, our goal is to discuss progress toward meeting Strategic Plan question objectives and to look at the progress toward meeting the aspirational goal of Question 7.

And I provided a couple of handouts for you all via email. And for the public, if you go to Meetings and Events Web page, you can access the materials there.

And so there are a couple of tables. One is the Cumulative Funding Table, which we went over in the last call. I'm not going to take us all the way through that table yet this time, but I am going to potentially refer to things in that table. And I wanted you to have it for background in terms of what has been funded over the past 5 years.

And the Committee members who were on the previous call used that to get a feel for the health of each of these objectives in terms of funding.

And on this call, we're really asking for invited experts to give us a sense of what's happening in the field? What accomplishments have been made? What are the remaining needs in these areas? And whether these objectives are still relevant, given the changes that have happened in the field over the past 5 years.

So to start, the thought was that we would go through each of the objectives and get some thoughts from the invited experts, as well as all of the people who are on the call. And then at the second part of the call, we would talk about the aspirational goal, hoping that some of the discussion of the objectives would help build toward that.

So if you'd turn your attention to the Conclusions Table, which is the kind of simpler table that we've provided for you, we have all of the objectives for the Question 7, which I think there are 16 objectives.

So I'd like to just point out that in the second column in this table, we've summarized what the previous call members concluded based on the data that they had about funding and some of the information that they were able to bring in in terms of other projects they were aware of or other kinds of progress that have been made. But we'd like to get some further discussion about this.

So for objective 7A: "Conduct a needs assessment to determine how to merge or link administrative and/or surveillance databases that allow for tracking the involvement of people living with ASD in health care, education, and social services by 2009.”

And the Planning Group was not aware of any projects or funding in this area. And the question for this Group is, is this needs assessment still needed, or has the field moved beyond the need for a needs assessment? Are there barriers? And are there efforts to link these databases already underway, maybe in places that we haven't been able to document through the portfolio analysis process?

So anyone that has any comments on this?

[Pause]

Dr. Durkin: Well, this is Maureen Durkin. I mean, I think there's certainly variance to it, and maybe that's why it hasn't been done. Having to do with just limitations on being able to link administrative data sets and concerns about privacy.

Dr. Susan Daniels: Okay. Other thoughts?

Mr. Hall: Yeah, I mean, that's the primary barrier, I believe as well. You know, we have done some things with our subject identifier to be identified subjects in CDC and, you know, with IAN, which is not technically administrative database, but, you know.

So I mean, I think these things can be overcome, certainly. And I think there is value in, you know, making these types of repositories broadly available.

Ms. Singer: I think there was also a question from the members of the Committee as to whether this type of project was research focused or whether it was more services delivery focused. It might be more appropriate to include in the services plan than the research plan.

Dr. Julie Daniels: I suspect it could be both, to be honest. And I mean, I think that there are -- theoretically would be a lot of value to data linkages with the evolving medical records that are becoming electronically forced and things like that.

But again, the issue surrounding privacy and access has been, you know, not negligibly challenging. And I think that, you know, any one database alone is limited, and it's really the combination that gives a lot of information. And that's where the big link is.

But I think that both service provision and research could really benefit from such things.

Dr. Susan Daniels: Who is speaking there?

Dr. Julie Daniels: Sorry. It's Julie Daniels.

Dr. Susan Daniels: Oh, thanks.

Any other points that folks want to make about this particular objective? Sounds like you're saying that it's still an appropriate objective, something that is still needed, but there are certain barriers, and progress is needed in terms of trying to find ways to overcome those barriers?

Mr. Hall: Yeah. And I think that's what the Plan says. It's sort of, you know, how can this be done? And somebody's not taking that on to really report back to the IACC on what would be -- what is possible. Because it's not implement surveillance, it's implement the plan on how this could be accomplished with existing tools and resources.

Dr. Susan Daniels: Is this something that you envision the Government taking the primary role or the private sector? Or who would be the key players to make something like this happen?

Mr. Hall: It's a concerted effort.

Dr. Susan Daniels: Or public/private partnerships. Okay. Are there any other comments before we move on to the next one?

So 7B: “Conduct an annual ‘State of the States’ assessment of existing state programs and supports for people and families living with ASD by 2011.”

Our Office followed up after the previous call to find out what was happening with the CMS project on the State of the States. And they let us know that they anticipate releasing a report on this in 2014. They have had an ongoing project, and that project is coming to completion.

I don't know if there's anything else that others on the call would like to discuss about that. We hope that we can invite CMS to come to the IACC and give a presentation on this when they finally release their report. And they've indicated that they're willing to do that.

Dr. Insel: Susan, this is Tom. I haven't actually looked at it carefully, but there's a book out recently called Autism in America that attempts to do pretty much just what we have asked for with the State of the States. And I wonder if this has already been done by someone with a pretty careful comparison of what's available, whether this is something that, even though maybe it wasn't paid for by the Government, is no longer needed.

I don't know. It may make sense for somebody to take a close look at that and determine if that would be sufficient. Maybe someone else on the call would know about this?

Dr. Susan Daniels: Anyone else familiar with that?

That sounds like, if that book is out and if it does have data that would contribute toward this, then we may have two different sources then, because CMS is pretty much finishing their project and ready to share their data publicly, soon hopefully.

Dr. Julie Daniels: Do you know who that book comes -- who published that?

Dr. Insel: You know, because I'm traveling I don't have access to that right now. But we can follow up. I just -- I've heard about this quite a bit at the American Academy meetings recently. There's a lot of interest in this topic. And people I talked to thought this was really quite an extraordinary contribution.

So let's -- maybe someone from the IACC -- from OARC -- can just take a look at this and see whether it's something that we may want to distribute or at least point people to it.

Dr. Susan Daniels: So I've heard that the book is *Autism Services Across America*, by Peter Doehring.

Dr. Insel: That's it. Yes.

Dr. Susan Daniels: So we can take a look at that, and we can also pass around a link to the book. I'm sure it's in Amazon.

Alright, so we're ready. Let's move on to 7C: "Develop and have available to the research community means by which to merge or link databases that allow for tracking the involvement of people in ASD research by 2010.”

On this one, the Committee last time concluded that the recommended budget was met and that there were a number of diverse projects that were attempting to pursue goals that were related to this objective.

Do people on the call, do any of you experts, have other information about this and the status of results that they've seen or changes they've seen in the field?

Mr. Hall: So yeah. My comment on this is that we have -- you know -- the community has implemented and made available, you know, this means of connecting all these databases. And we have -- the NIMH's, the NIH's NDAR, IAN, Autism Speaks agree all linked up; SFARI is coming online soon.

So we've done that. We've made it available. But I guess when we get into the aspirational goals; I think we're going to talk about just having it available. And then really promoting this for the community at large and how we can get, you know, tens or hundreds of thousands of subjects to come online, give their information, overlay the data, and make that available for resource community is really where we need to get to.

You know, right now I think we have, you know, 40,000 people registered in IAN. We have 70,000 subjects in NDAR. But even though these are quite impressive numbers, they're really not impressive when you look at aspirational goals of really what could be made available.

Dr. Susan Daniels: Thanks.

Dr. Insel: Dan, this is Tom. I think what you just said is very important for what the final report will look like. And you know, what would be great for us is if we could ultimately, especially all the way through Question 7, think about having a table that says, "This is what we have in 2009. This is what we have in November of 2013." And show what's grown and what hasn't and where the opportunities are.

We can still define what needs to be done, but I think it would be really critical for -- even more important than seeing the dollars would be to actually see the numbers.

Because I have to sign off in a couple of minutes, I just want to make sure I get this point in. Almost every one of these items that are coming out, we need to actually show what the specific growth or lack of growth is, the actual numbers that we've got. So if it's 40,000 now, it would be great to know, if we can get the number, of what it was in 2009 when the Plan started.

Mr. Hall: Sure. And then how to capitalize, you know, on that.

Dr. Insel: Right.

Mr. Hall: You know, what's the next step to get us, you know, over to the next level? So we do have a lot. And it's just a matter of appropriately using these resources.

Dr. Insel: Yeah. I mean, if you -- so if cystic fibrosis, I think, at this point, we have probably 100 percent of children with cystic fibrosis who are in the registry. It would be interesting to know presumably the one million of people with ASD, this would be under the age of 18

-- 40,000 seems like a lot, but relative to a million, it's a small percentage.

Mr. Hall: Yeah. [Inaudible comment]

Dr. Insel: Those kinds of numbers should be helpful for us, especially as we go into that final meeting in November, late in November.

Mr. Hall: Okay. I mean, I think we can take that as an action item and probably fill that out.

Dr. Insel: Great.

Dr. Susan Daniels: Alright. Any other comments on that one?

If not, let's move to 7D: "Establish and maintain an international network of bio-banks for the collection of brain tissue, fibroblasts for pluripotent stem cells, and other tissue or biological material, by acquisition sites that use standardized protocols for phenotyping, collection, and regulated distribution of limited samples by 2011."

And there are a number of sub-bullets here. And I think everyone has access to the table, so I'm not going to read that entire objective.

But the Group concluded a recommended budget was partially met, that progress has been made, but there are still needs in this area, significant needs. I added our Group, OARC, got some more information about the current efforts for the NIH neurobiobank, and we've added that information here that NIH funded five brain-banks in a new bio-bank initiative in 2013, just recently. And that was a $5-million effort, but those dollars won't be reflected in here because they were a broader set of disorders than just autism.

And there is a private effort underway as well, but we didn't have access to information about what the status is on that. We could try to seek that out.

Ms. Singer: Is that the brain-bank that's being funded by the Simons Foundation?

Dr. Susan Daniels: Yeah. So I wasn't able to get information about that. We just didn't have time to be able to reach out to them to find out what the latest is. But you may know. So do you have any information?

Ms. Singer: Yeah. So an effort is underway to launch what would be called the Autism BrainNet. And it will start with four nodes: one at the MIND Institute, one in Texas, one at Mount Sinai, and one in Boston.

And the idea is for there to be standardized collection protocols and a single scientific advisory board that would oversee the distribution of tissue to the most relevant projects, based on merit, as opposed to based on the location where the brain was collected.

So this is expected to be launched, I'd say, early in 2014. And it will be accompanied by a Chapter 2 objective, which is an awareness campaign for the general public that's designed to encourage and make aware to the general public the need for people with autism and people in the general population to donate brain tissue for autism research.

Dr. Susan Daniels: Thanks for that update. We can add some information in here about that.

Dr. Insel: Here again, Susan, I just encourage the Group to come up with specific numbers. So it would be helpful to know how many brains, how many

DNA samples, how many fiber-glass.

Ms. Singer: Yes.

Dr. Insel: And it would be useful, if we can, to say, you know, this is where we were in 2009, and this is where we are in 2013.

I think, for DNA and fiber-glass, you'll see an extraordinary increase, because we know the numbers. For brain, it's going to be a conspicuous lack of growth. Actually, it might have gone down -

Ms. Singer: It's gone down. It's gone down because of the loss of the brains from the Bockmann freezer failure.

Dr. Insel: That's important to show here. I think this is our, the one question where we ought to -- the whole thing can actually just be a table. I'm not even sure how much text we need for this. We ought to keep this quantitative so people can see where the growth is and where the needs are.

Dr. Susan Daniels: Okay. Offline, maybe we can talk about who we’ll contact to get that information.

We also did have some information about the brain span atlas and the funding for that. And those numbers are also not reflected here because it's a broader effort than just autism.

Dr. Insel: Yeah, but that's great. I think that's maybe the most important thing that's been done. In fact, I would argue it is the most important thing that's been done. And even though it never has the word "autism" in it, it's going to really be transformative for this field. So I think you have to let people know about that, especially since it's public access.

Thomas Lehner will be able to give us all the numbers for the IPS fibroblasts for DNA, all that.

Dr. Susan Daniels: Okay. Okay. Great. So with the new NIH neurobiobank and the private effort, the Autism BrainNets that are launched now, what are -- I guess all of that sounds like it's very promising. Those are moves in the right direction. But are there any particular gaps or additional things that you think might not be being addressed by those efforts that you would want to know?

Mr. Hall: My view is that both of these

efforts are outstanding and that, you know, this area is critical. And you know resources are being put there. You know, my only emphasis would be to ensure that there's some consistency across these two efforts to make sure that there is -- you know, that it's not

-- you know, we get the sum of the parts here, or greater than the sum of the parts in, you know, these efforts for this critical area.

Dr. Susan Daniels: Great. We can add a note about that.

Dr. Niu: Hi, this is Stan. I'd like to make a comment.

Dr. Susan Daniels: Sure.

Dr. Niu: This group, which also identify the brain tissues collected by individual researchers. The reason I'm stating that, because one of our funded FY07 project, that group actually had a collection of, I believe, up to 72 brain samples. And they did that pathology and a lot of characterization.

I'm just wondering if, you know, we can ask those researchers in some way to share those tissues, then we can make, you know, increased number of brains available for this area.

Dr. Susan Daniels: So maybe we can talk offline about that, too.

Dr. Niu: Okay.

Dr. Susan Daniels: Putting you in touch with the right people.

Dr. Niu: Sure. Thanks.

Dr. Susan Daniels: Anything else that anyone wants to discuss for this objective?

If not, let's move on to the next one, 7E: "Begin development of a web-based toolbox to assist researchers in effectively and responsibly disseminating their findings to the community, including people with ASD, their families, and health practitioners by 2011."

And the Group on the last discussion concluded, based on the information that was available, that the recommended budget has been met, but few projects were categorized to the objective. And that was partially because some of the intent of this objective was achieved through other mechanisms, not through a web-based toolbox.

Do people want to elaborate on that?

Mr. Hall: Yeah. I mean, I'll elaborate on this objective. You know, one of the things that we did with the National Database for Autism Research that we have available now, and we are trying to convince the research community to use, is that we can set up any publication and then the underlying data under that publication for essentially every human subject's grant.

And we've gotten some traction with that about, you know, 10 or 15 publications are now there, where right from PubMed, you can click on a link and, you know, the general public has access to, you know, all of the details, summary details of that publication. And then approved scientists can then download that data.

And you know, we feel very strongly that these types of results should be made available. And I know back in 2009, there was this aspirational goal of, you know, share all data. And now we're talking about results. And we do have this capability, and we do have this toolbox available.

And it's just a matter of encouraging the community to use it, because, you know, this is really a way to responsibly disseminate results. And we feel we can accommodate all human subjects’ research this way.

Dr. Susan Daniels: And so, Dan, is this tool primarily targeted at researchers sharing with researchers? Or with the public, or --

Mr. Hall: It's both. I mean, it's -- you know, unfortunately, it's human subjects data underneath. And you have to be a qualified researcher. It's protected in that way. But it does provide a mechanism to, you know, see the exact methods and information used for any type of important finding.

And for researchers who have access to be able to download and look to, you know, replicate results quite -- you know, much more simply than it would have been possible before, you know, the infrastructure that we've built existed.

Dr. Susan Daniels: Thank you.

Do any others have comments about this, things you've heard of in the field that contribute toward this? I think Cathy Rice had some more examples. And so I'll try to get some information from her about the CDC examples.

Mr. Hall: And from our perspective, if anyone wants to go look at this, it's called Data from Papers. And, you know, we can set out the link. But you can see those that have done this, how they've organized their data specific to cohort and measures and are sharing, you know, their findings with the community.

Dr. Susan Daniels: For folks that are researchers on the call, are there other kinds of tools that you would like to see available to help you disseminate your findings to the community?

Dr. Julie Daniels: Well, one thing -- this is Julie speaking again. I mean, one thing, and I'm not sure. Where this fits into the bigger picture, but for families, I think that important missing link is that we depend a lot on web-based tools to disseminate information to people. And I think that probably hits the majority.

But I worry that there are still some underserved populations that don't have Web access. And whether there are any initiatives to bring information to them through providers or other means.

Dr. Susan Daniels: Okay.

Dr. Julie Daniels: Maybe that's a separate issue from this and doesn't belong here, but I just wanted to put it out.

Mr. Hall: Quite relevant, yeah.

Dr. Susan Daniels: No, I think it's relevant. It's all people with ASD, those who have various levels of needs and resources.

Dr. Durkin: I wonder also about the costs of publications and making things open access. I know that if it's federally funded, after 1 year it becomes available. But in that interim, it's sometimes hard to be able to disseminate findings unless it's published in an open source.

Dr. Susan Daniels: I don't know what the latest is on open-access policy.

Anyone else?

Mr. Hall: I mean, you know, yeah, abstracts and things like that are available that are more targeted than, you know, the general public. But those that are, you know, out there on their own, they don't know these services are available. So you know, it's almost like the data is there, it's just getting the data distributed to the -- you know -- those affected, you know, through social media and other outlets.

You know, somebody -- you know, there needs to be a transition from a finding and what the meaning of that is to those that are affected out there, because they can't be expected to learn the intricacies of the science.

Dr. Julie Daniels: I think that some of the foundations have taken that on through newsletters and things like that that distribute it and have a research component, too.

Mr. Hall: Yeah.

Dr. Julie Daniels: To disseminating research results. I think what could take it a step further would be to provide some sort of cataloging so that, you know, they miss the newsletter, and a year later you're interested in these topics that might have been covered then. Is there a search engine or something by which the lay public can -- I mean, PubMed is great, but it's over whelming.

And I'm just not sure if there's a way to sort of move something forward that would be more accessible to laypeople, as far as search terms or something to find things that are most up to date and relevant.

Ms. Singer: Well, I think the Simons Foundation, Autism Speaks, and the Autism Science Foundation -- we all catalog the research and have it searched for by topic, searched for by key words, searched for by publication date, by post office. And we try -- I think all three of them really try to make the information lay friendly.

But then it links -- we do try to link to the full text, at least the abstracts but as often as we can the full text.

Dr. Julie Daniels: Yeah, so maybe it's [Inaudible comment]. The only thing I wasn't sure about if all of the organizations did that I know, some did, sounds great.

Ms. Singer: But maybe we want say that. That, you know, there have been efforts over the last few years, though different Web sites, to bring this information more directly to stakeholders.

Dr. Julie Daniels: Yeah, I would think you would want to acknowledge those efforts as successes.

Dr. Susan Daniels: Yes. We need to put some information about that in here, and those Web sites – the ASF, Autism Speaks, and Simons Foundation Web sites -- all are excellent, and it's quite easy to search for information about publications that may have been older. If you want to find anything, it's really pretty easy to access. So that certainly has been an advance in this area.

Are there any other items that people want to mention for this one?

Dr. Durkin: Well, you mentioned that Cathy Rice is going to give you information. But I would just say, I know on the CDC there's -- it's possible to identify research findings, too, and papers that have been published. Although I don't know that you can get the actual papers.

And then, they have a big effort in, you know, community outreach and developing -- act early the signs, that kind of information. And I don't know if that's related here, because I don't really research findings. But it's information that is accessible to the public about -- some of it's about the latest findings in autism, and some of it is about early identification.

Dr. Susan Daniels: Right.

Dr. Durkin: All of our surveillance reports do come with a community report, and that's available through that Web site.

Dr. Susan Daniels: Right. Great. Anything else?

Dr. Paul Law: This is Paul. I apologize for joining late. Can you guys hear me?

Dr. Susan Daniels: Yes. Welcome, Paul.

Dr. Law: For a while, I was talking to myself, until I got patched in.

So at IAN , pretty much everything we do, there's a community report and, you know, the publication that goes with it. So, interesting -- whoever just spoke, we can actually use the same term. The community report is well done, extremely attractive, and has been the highlight of our Web site.

You know, in the case of the wandering research project, that community report, you can find it on references to it on other Web sites on Google, more than 500,000 different references to it.

But going back to the issue of open sources, most -- there's a few open-source journals that have a good reputation, like PLOS. But for the most part, the better journals, the ones that researchers want to get their findings into are not open source. And the non-open-source journals are ones that the researcher does not need to pay to get their article into, whereas most open-source journals require that you pay a certain amount.

So that actually, there are incentives for the researcher to -- a couple of disincentives to publish open-source journals.

Dr. Durkin: I agree, one of the things, though, some journals you can -- good journals, you can pay to have it. You know, $1,500 and then it becomes open source even though it's still a journal.

Dr. Insel: I am going to have to sign-off. Sorry, no. I just wanted to let you know. Sorry I can't get on the call.

Dr. Cathy Rice: This is Cathy Rice I am signing on.

Dr. Susan Daniels: Thanks, Tom.

Dr. Insel: Okay. Great. Rotating chairs here. Thanks. Bye-bye.

Dr. Susan Daniels: Welcome, Cathy. We were just discussing Objective 7E on the web-based toolbox. And I know that on the last call, you said the CDC had a number of tools that were not in the toolbox.

But do you have a couple of comments about what those are?

Dr. Cathy Rice: So, the toolbox for disseminating research findings?

Dr. Susan Daniels: Yes.

Dr. Rice: I think they're similar to what Paul was just mentioning for IAN in that we have Web communications. We have community reports and brief key-point summaries of any research studies that we fund and that come out, that are all available on the Web. But it's not necessarily a toolbox.

Dr. Susan Daniels: Okay.

Dr. Rice: And then we work directly with grantees that we have in terms of providing feedback and support and guidance on disseminating research findings if it's their -- as requested, if it's their -- if it's more of a grant-based project. And if it's a cooperative agreement where CDC is engaged as well, then we utilize our communications services to develop those summary documents that are more lay friendly.

Dr. Susan Daniels: Thank you. We'll take note of that as well.

So if there aren't any other comments on this -- I think we've heard several ideas for this, which his great -- we'll move on to 7F: "Create funding mechanisms that encourage rapid replication studies of novel or critical findings by 2011."

And the Group last time concluded that there were no projects in this area that were funded through grants and noted that the creation of funding mechanisms or initiatives is not likely to be achieved by grant. So that's why it's not in the portfolio. And the Group also discussed the possibility that it might be too early for replication studies to be a significant focus, as the current focus is mostly on primary studies.

But does anyone have any comments about that?

Mr. Hall: Yeah. My comment is I'm not so sure that it's too early to do that. I mean, we have data now across multiple repositories. You know, we have data on 70,000 subjects, 7,000 exomes, 2,500 MRIs. So you know, there is this infrastructure that can be utilized to do this type of thing. You know, nobody is funded to do a replication of a key finding, but certainly there's data that could support that type of replication.

And you know, we are doing a lot with computational software and pipelines, where we are overlaying omic alterations, imaging volumetric results, and bringing these types of things back. So in some ways, you know, the infrastructure is there, but the funding mechanism isn't.

And you know, it's pretty dicey, but I think it's a lot cheaper to do now than it was 18 months ago.

Dr. Durkin: This is Maureen Durkin. I agree completely. I don't think it's too early at all to be doing replication studies. I think that's critical.

I think the only question is whether there should be a separate funding mechanism for it, or if there are other funding mechanisms used to do it.

Ms. Singer: Well, I think when we wrote this objective, the idea was that there should be some separate funding so that -- really emphasizing the idea of rapid. So that if we had a breakthrough or we had something critical, it could be rapidly replicated.

Dr. Rice: A fast-track opportunity for funding.

Ms. Singer: Exactly. That was sort of the intention of the objective.

Mr. Hall: I mean, but you know, I guess at least -- you know, I think it's entirely possible to do this now.

Ms. Singer: So maybe…Are there any examples of the types of studies or specific studies where rapid replication, had there been specific funding for this, would have been beneficial to the field? Maybe if we could give some examples.

Mr. Hall: Yeah. I think when we're looking at, you know, regions of interest in imaging studies, when we're talking about, you know, potential copy-number variations that have been found, you know, these types of things can be shown and proven on, you know, the data that, if it's NIH funded, that should have already been made available and shared, as well as, you know, all this other data that we have from Autism Speaks, Simons Foundation.

So you could look at those omic alterations and see if, you know, these reports, you know, on 300 or 500 subjects, if that replicates for scales to, you know, on 6,000 subjects. And that's really where we need to go, in my opinion.

I think those types of findings, you know, IQ variations, you know, that have come out, you know, the data is there to look to replicate by appropriate scientists to take this on.

Dr. Rice: This is Cathy. If I can add, I think going back to the original intent, I was thinking that this was more geared toward findings that are directly relevant to treatment implementation.

So maybe I'm thinking too narrowly here. But those that -- so, for instance, an old example was when Secretin was quickly being disseminated as a new treatment and being utilized in a variety of places. And there was a very quick effort to do randomized controlled trials and really look at the effect of that. And they were mainly negative studies, and it quickly had a big impact on what was happening with direct treatment to children.

So I think a similar example, if we'd had -- there was more success in some of the recent medication trials that were happening, that would be an example of something that may be directly relevant to intervention related to particular symptoms of autism. And so you know, I think a discussion of, are we talking about more basic research findings? Or are we really talking about fast-tracking findings with potential short-term immediate clinical applicability and evaluating the utility of those types of interventions?

Mr. Hall: My response would be both, all of the above. So I mean, I think that's a perfectly valid example. Like not everything can be replicated just on the data, but some can. And you know, these types of things need to -- you know, we need to have -- we need to be prepared and hit the ground running when a finding comes along that, you know, shows promise.

And so you know, we need to set up some type of infrastructure to support that. And you know, I think the time is now for that.

Dr. Susan Daniels: So does the Group feel that special funding mechanisms are the way to achieve this?

Mr. Hall: Well, I mean, it's complex. But I mean, I don't think you can say, "This is how we're going to do it." It's -- I mean, I think you can set it up to support, you know, like from an NIH perspective, special – and this is -- panels and do things very fast. Fund, you know, some researchers who are, you know, looking at secondary analysis and replicating data that way.

Looking at the data that should have been shared that supported this promising finding, but is not shared. And validate the methods used. I mean, these things are absolutely within our grasp. They just need to be followed through on.

Dr. Rice: I think it gets difficult when we're talking about a special mechanism because --

Mr. Hall: Yes.

Dr. Rice: I think most researchers would argue that things that they are funded for and the findings that they have are important and useful and should be replicated immediately. And so where do you draw the line between a special pipeline versus the ongoing research that's reflected in the entire Plan?

That's what brought me earlier to thinking there is -- this, to me, applies in terms of having a special mechanism, if we define it in a way of really trying to fast-track research that has direct, immediate, clinical implications for intervention.

Mr. Hall: Right.

Dr. Rice: Whether it's a logic intervention or even if it's a behavioral intervention that is showing significant promise and needs immediate replication or needs, you know, effectiveness studies. It's shown to be efficacious, but is it really effective in the community?

So I could see a separate mechanism for that type of very clearly targeted -- something that could have an impact on the lives of people with autism within the next year if it turns out to be a useful intervention. But otherwise, I don't really see where having a separate mechanism is going to be helpful because that's the process of typical research, is being able to, you know, submit funding. And it would be hard to distinguish what is crucial and what is not.

Dr. Law: This is Paul. So I think I'm agreeing a lot with Cathy on this. For me, the question is, who are the actors? So somebody decided that there was research that was critical. So somehow, the actor has to be defined as -- this can't [Inaudible comment] passive situation that somehow just is really across all NIH institutes and, you know, private funding locations.

It needs to be somebody who decides that there's some critical research that needs to be reproduced or replicated or -- I don't even like the word "replicated" because I think a lot of times, research is -- replication implies almost like copying the research exactly as it was done, as opposed to sometimes coming at the same conclusion through a different type of study design.

Might be the prefer way of going about it -- that there needed to be an actor. The thing is, I think, for this to work, there needs to be a mechanism that is overseeing the process. Otherwise, I don't see how this actually happens.

Mr. Hall: Well, you know, today in the real -- you know, I guess, at least here at the NIH, if there is a finding, you know, that's deemed appropriate, I think that, you know, there are mechanisms, you know, for supplements and things like that that may not be getting reported here.

You know, the mechanisms are in place on that type of thing. But you know, there are -- you know -- there are other capabilities that exist now that should also be looked into that are out -- you know, a different way of doing research that is a possibility. And that, you know, should be pursued.

You know, none of these things cover the full gamut. But at least an acknowledgment on different methods to support, you know, a corroboration of results is critical. And you know, right now, it's not -- you know, it's -- you know there's not anything specific. It's really handled at the grassroots level. But I think there is opportunity to do things more on a broader scale, larger level.

Dr. Law: So whose behavior are you trying to alter by this amazing information about other ways of replicating or reproducing findings? The institutes or researchers or --

Mr. Hall: Yeah. Well, it's -- I mean, you know, the knowledge base of a particular finding, you know, to wait 2 years or something like that or, you know, to get a team set up to do this independently is kind of slow. And there are some things that can be replicated, especially in omics and imaging and EEG that can be done much faster now.

So I'm not saying that, you know, for a clinic, you know, that there's this new opportunity out there for, you know, this clinical trial and, you know, that that should be bypassed, those kinds of things. But you know, there are other areas that were set up and have infrastructure to support this type of thing or at least ensure that the -- you know, a critical finding like something that -- you know, appeared in *Nature* last week on identifying, you know, autism at 6 months old, that that data is shared and others can look to, you know, understand the full methods of that.

Dr. Law: Right. Yeah, so the first step in being able to replicate findings is actually to be able to look and see what the original researcher did.

Mr. Hall: Definitely.

Dr. Law: What you were saying before about the transparency, concepts of grade -- studies can be robust and link to the original data set, and, you know, even to their analytic files used to --

Mr. Hall: Yeah, even to the software that was used to come up with that result.

Mr. Hall: Yeah.

Mr. Hall: So basically, I think, I guess, you know, what I'm advocating is that there are other tools and resources available today that have not typically been used before, and that, you know, I think we're in a better place to do these types of results replication.

And you're right. I shouldn't say "results replication." It's corroboration of results, you know, faster and better than we've done before.

Dr. Susan Daniels: This is Susan. In terms of getting the funding out, though, their supplements are a fairly fast method, but one of the challenges with this is if a finding comes up and you don't know when it's going to come, for NIH anyway and some of the Government agencies --

Mr. Hall: Yeah.

Dr. Susan Daniels: -- it's tough to know when you're going to -- if you were going to do this, say, through an RFA; the RFA comes up once. And if it didn't happen to match the timing of this great finding, it won't be useful.

So that might not be an appropriate kind of mechanism, although I don't know if that was meant when the Committee came up with this. But --

Mr. Hall: But I mean, to me it's all findings. And certainly, some things you need to establish and do a clinical trial with. But clinical trials are expensive. And we can't do clinical trials on every replication that's out there.

But there are, you know, more efficient ways that are possible that -- you know, that we can start moving toward in supporting this initiative.

Dr. Susan Daniels: All right. So are there any other discussion points that people want to make on that one?

Dr. Durkin: This is Maureen Durkin. I would just say I think that the replication work is extremely important. Somebody asked for an example. And just as an example from Alzheimer's disease, I remember many years ago when the APOE finding was made based on a relatively small clinical study, I think, in a small sample, non-representative, at Duke.

And then different population cohorts around the country were able to replicate it, based on population-based samples. And it was really valuable to really establish it.

So I think having some mechanism to encourage that would certainly help advance the field.

Mr. Hall: Yes.

Dr. Durkin: And especially in autism, where most of our research is based on pretty non-representative samples.

Dr. Susan Daniels: All right. Are we ready to move on to 7G? And we've got about a little bit less than an hour left on the call. “Develop a web-based tool that provides population estimates of ASD prevalence for States, based on the most recent prevalence range and average identified by the ADDM Network by 2012.”

And the comment that we had from the Planning Group last time was that autism tracking data captured in CDC's environmental tracking tool is not reflected in the portfolio analysis figures because it's not specific to autism. But that the intent of the objective has been accomplished through the CDC project.

Is there anything else that others have to add to that?

[Pause]

Cathy, anything that you want to add or --

Dr. Rice: No. I think that captures it. Just the environmental -- CDC's environmental -- public health tracking tool includes the autism instruments from ADDM as well as other conditions and allows you to search in a variety of ways based on the web-based tools. So I'm not sure what else we would do with that one at this point.

Dr. Susan Daniels: Okay. So then that one sounds like it could be considered completed and maybe make room for other continuing objectives that still need to be accomplished.

Dr. Rice: Yeah.

Dr. Susan Daniels: Let's move on to 7H: "Create mechanisms to specifically support the contribution of data from 90 percent of newly initiated projects, the NDAR, National Database for Autism Research, and link NDAR with other existing data resources by 2012.”

And from the last call, since then, we have been talking with NDAR and have gotten some more information, and quite a bit of this objective has been accomplished, but I'll let Dan Hall elaborate on that.

Mr. Hall: Sure. So you know we have terms going out in all of NIH's grants supporting data sharing. We are connected to all these different repositories. And you know, we are working with Autism Science Foundation and the Department of Defense, the State of New Jersey, to bring all this data into NDAR at a raw level.

As well as, you know, have a mechanism, as I indicated before, to show results that were now -- that's really at the level that we're at.

In 2012, 81 percent of NIH's human subjects’ grants had this in there. And you know, we're fairly confident that we reached it in 2013. We don't have the data to do the analysis just yet. So you know, this data is out there, I guess. From an NDAR perspective, you know, we've had pretty good results in the last year. We now have 250 scientists at 71 labs across 10 countries who have, you know, requested access to this data.

We are seeing publications coming in now, you know, using NDAR as really the data repository. And I think the most encouraging is that we're seeing a lot of grant applications coming in, you know, adding this as an aim to their existing research for, you know, a site that does, you know, has a finding to corroborate it on a much larger pool, if applicable.

So you know these are the things that we're working on. You know, I guess as we go forward, you know, we have all this data in the cloud -- you know, 8,000 exomes, 2,500 images -- and, you know, there is a real opportunity for us to integrate computational pipelines. And we're working with a number of labs to move their pipelines into the cloud and make these -- the pipelines, software, and the results available, just to layer on existing data to really expand upon the utility of what can be done.

Dr. Susan Daniels: Great. And you'd let us know that 81 percent of extramurally funded studies now are contributing data?

Mr. Hall: Yes.

Dr. Susan Daniels: NDAR.

Mr. Hall: As well as all these other agencies that I mentioned. You know, we are coming online this year with SFARI, which will be federated. AGRE is federated. IAN is federated. So you know, we think that we're close on this aspirational goal as put down in 2009, I guess.

Dr. Susan Daniels: So if you're at 81 percent now, hopefully within the next couple of years get to 90 percent?

Mr. Hall: Yeah. Yeah, we don't expect -- you know, we expect to be at 100 percent. But there might be something that sneaks by some other institute.

Dr. Susan Daniels: Great. Does anyone else have comments on this one?

[Pause]

So I guess, you know, you would want to be continuing this effort. But in terms of the objective, do you feel like the objective is close to complete?

Mr. Hall: You know I do. And I think going back to what Tom said on -- you know, we did this objective. We have all this data. You know, I think our new aspirational goal is, we want 90 percent of the publications on human subjects with that data specific to that publication be shared.

And I think that's something that we should strive toward over the next 3 or 4 years to, you know, really provide transparency on results and make that available to everybody and aggregate across, you know, all of this work that's being done, to just make this resource, you know, greater utility to the community.

Ms. Singer: To Tom's point earlier about some data, there's no big, great place to show the increase in the donation rates since 2009 to the present.

Dr. Susan Daniels: Okay.

Ms. Singer: Do you have -- I know the number for this year is 81 percent. But do you have the numbers going back by year to 2009?

Mr. Hall: Yeah. Yeah. Absolutely. I mean, we could show it at the ground level or at the -- you know, or for the -- funding organization level, potentially. But really, it's the number of subjects, you know, available and the quantity.

I should also mention, you know, the quality of data as it’s increasing. So we have those statistics, too. I'm not sure just, you know, 80 percent of the grant-sharing data. Because that's, you know, a little abstract. But, you know, what's available and what's coming online, we have 200 terrabytes of omics data that can be computed in an instant. And the Amazon cloud, you know, these are the types of things that would be more relevant.

Ms. Singer: I'm just saying that this is a great success story, and we really shouldn't underplay it.

Mr. Hall: Okay. It's really not my -- you know, I probably overplay my hand too much. So yeah, we can provide those numbers, and potentially, I guess, next week.

Dr. Susan Daniels: Yes. That would be great.

So it sounds like the Group thinks that this one is close to complete. And then, Dan, you provided a possible next step or a next goal in terms of being able to really share publication data more widely. So that might be something that we can bring up in the workshop next week as a possible future direction in this area.

Mr. Hall: And if I could put my own pet aspirational goal out there, and, you know, Paul and I have talked about this a lot, is that, you know, we've now linked up all this research data, and there is a component for the community to -- through IAN -- to provide their experiences. So we have these kind of capabilities there.

One area that could be a future initiative is that it would be quite easy, not for the Federal Government to do this, but somebody else to establish a way for a family to consent, share, you know, where they live, you know, over the course of, you know, their experiences with autism.

And we have the omics and proteomic-imaging type data. And so it would then be possible to overlay environmental data down to the house level and have that data be identified but made available to the epidemiological community, as well as looking for environmental factors as they influence genetic factors. And I think this is a huge opportunity that I don't want to miss.

Dr. Susan Daniels: Great. We can maybe bring that up at the Question 3 call, because they might be interested in that.

Okay. So moving on to 7I: “Supplement existing ADDM Network sites to use population-based surveillance data to conduct at least five hypothesis-driven analyses evaluating factors that may contribute to changes in ASD prevalence by 2012.”

And on the last call, the Group concluded that the recommended budget has been met, although the entire budget of the ADDM Network sites are included in this figure because there wasn't a way to separate them out. And so, all of the ADDM funding is here. And initially, ADDM supplements were used to achieve this, but now that the ADDM sites are more fully operational, they're actually doing this work without supplements -- was my understanding from the last call.

Is there anything else that you all would like to add or discuss with regard to this?

Dr. Rice: This is Cathy. Just to clarify, with the initial supplements, there was never a separate existing data analysis supplement mechanism. Several of the sites did get supplemental funding from other sources to use the data that they had collected.

Dr. Susan Daniels: Okay.

Dr. Rice: I just want to give inappropriate credit. I think that was the intent, to be able to give those types of funding supplements. But it was really just folded into the expectations and funding of the base ADDM program.

Dr. Durkin: This is Maureen Durkin. I just want to mention that, yeah, this was news to me that there were any supplements. We operate on a complete shoestring as far as any -- there's no funding in the ADDM budget for analysis or research papers. It comes entirely out of our own --

Ms. Singer: But I thought that, for example, Autism Speaks had provided funding to do additional analysis on the ADDM data at the ADDM site. Is that not correct?

Dr. Rice: Yeah. They have for some sites that have applied for that. So that's one of the mechanisms where sites have pursued other outside funding, and Autism Speaks is one funder. The New Jersey Governor's Council is another funder, where specific sites have applied and received that funding.

And then how it works now is that, although there are -- not really sufficient funds to do extensive analyses, each ADDM grantee is expected to initiate analyses and outside of the general prevalence report during their grant period.

Ms. Singer: I thought that this objective was really intended to home in on those supplements and that the idea was that there was this existing ADDM Network, which was an important piece of infrastructure in the autism community, and that this objective was intended to encourage the community to leverage that infrastructure by providing supplemental grants that made use of the existing data collection.

And I think the fact that the entire ADDM budget is thrown in this line really makes it look like a lot more work is being done in terms of supplementing and leveraging the existing work that is actually happening.

Is there any way to tease out the money that -- the agencies that you just said -- Autism Speaks and New Jersey Council, et cetera -- to list that money as going into subjective and pull out all of the -- you know, the $23 million looks -- I don't think it's correct to say that that's supplemental funding.

Dr. Rice: Yeah, I agree, Alison. Because I think the point of this really was to be above and beyond, you know, what's expected. And so that would be a more accurate reflection. We could ask the ADDM site if they have received any other outside funding to do analyses during this time period, to let us know.

Unless it -- some things, like Autism Speaks, that should have been something that was reported in what they've reported. But other things like the New Jersey Governor's Council, I believe some other states have put in some money. That's harder to account for, but we can definitely try to find out what that total is.

Dr. Julie Daniels: Cathy, I think that some of those state contributions weren't potentially to capitalize on the infrastructure to do measurements but to actually get the surveillance done as well.

Is that true or not?

Dr. Rice: In the case of New Jersey, they have got both.

Dr. Julie Daniels: Okay.

Dr. Durkin: Yeah. This is Maureen again. I think that my understanding of the Autism Speaks funding was to South Carolina; that was for a different thing, and it was supposed to appear somewhere else for the screening.

Dr. Susan Daniels: Right.

Dr. Durkin: But I wonder about those other fundings they have done.

Dr. Rice: They in the past had received

funding to do analyses of 15-year-old's medication data of a variety of things. It was a separate from the screening study.

Dr. Durkin: That's totally different though, from 7I, which talks about factors contributing to the increase in autism prevalence.

And then, I think that -- I don't know. Also, Autism Science Foundation did fund a graduate student to analyze the ADDM data once. But I suppose that could go in here.

Dr. Rice: Yeah. That's the type of thing.

Now, I mean, if we're talking about whether this objective is met, I think given that it's very patchy and has not really fully met -- it seems more like a partial meeting of it.

Dr. Susan Daniels: So, Cathy, you and I might need to talk offline about if you're going to be recoding --

Dr. Rice: Um-hmm.

Dr. Susan Daniels: -- different projects for 2011 and 2012. The 2008 through 2010 data is already locked and published.

Dr. Rice: Okay.

Dr. Susan Daniels: So that can't change. And if you're going to pull the ADDMs out of this objective, they may end up in "Other."

But we can talk about that offline, and I can also check to see other projects that were in here. There may be some other projects from other funders that are here.

Dr. Rice: And I think, you know, it is a question of where, then, is the appropriate place to put the ADDM funding? And I think it was put here because we don't have -- you know, it could be down in the expanding the site. But everything we have is based on the assumption that there will be the core ADDM sites that are built upon. We don't really have an objective about maintaining for looking at trends over time.

Dr. Susan Daniels: And that goes back to the discussion that we've had on all of the previous phone calls about the "Other" category and that that really was sort of the base or core activity funding --

Dr. Rice: Yeah.

Dr. Susan Daniels: -- and that these

objectives really are addressing gap areas.

Dr. Rice: Right.

Dr. Susan Daniels: So I think that this exercise that we've done this year is the first time the Committee has actually looked in this great of detail at the way that this is done. And I think now you all can get a sense of some of the dilemmas that we face in terms of trying to figure out with the funders where things fit.

And the Committee early on had told us that they really wanted to try to fit projects, as much as possible, into gap areas versus "Other" because I think maybe there was a misperception about what "Other" really was, which is really just baseline, core activities that were ongoing.

So you know, we can talk about it. OARC works with the funder to determine each of the categorizations for the portfolio analysis. So we'll work with CDC on that to make sure that, if they want to change how they're coding the ADDMs for the upcoming reports, that we get those changed before we lock the data.

Ms. Singer: That is something, Cathy, that came up on almost every call, that the objectives were to address gaps. And that it's really -- all of the core work has no place to go. And so one thing that I recall I should bring up at the IACC meeting that had to be cancelled because of the Government shutdown is changing what we call "Other" and calling it "Core."

Dr. Rice: Yeah. That would be good.

Dr. Susan Daniels: So, we can bring that up either, you know, via email, that might be…or we could have a discussion in January. January 14th is our next full IACC meeting. But we can certainly try to make that change in terminology.

Dr. Julie Daniels: What "Other"?

Dr. Susan Daniels: What?

Dr. Julie Daniels: [Inaudible comment] the vast majority of the stuff is in "Other." It makes no sense.

Dr. Susan Daniels: It's what has made sense for the past 3 years, as we didn't really have a title for it. I think in OARC we were aware of what it was. But having come up with a different name -- I think that the problem didn't become apparent to the Committee until now that we're going over this in fine detail. I think it finally is clicking. And I think the suggestion to change the name is great. So we will definitely talk about that with the Committee.

So if nobody objects, let's move on to 7J: "Develop the personnel and technical infrastructure to assist States, territories, and other countries that request assistance describing and investigating potential changes in the prevalence of ASD and other developmental disabilities by 2013."

And this one, the Group, on the last call, determined that they thought the recommended budget was partially met and that there are some projects that have been coded to other areas but aren't represented in this funding amount because they were coded according to the specific science areas they represented. And that CDC does provide personnel and help to the states, territories, and countries as requested.

But the budget for that would not be reflected in this number because it's not achieved through grants. So, and that more progress is needed in this area.

Do you have other comments about this?

Dr. Rice: That captures it from a CDC perspective.

Dr. Susan Daniels: Anything else from our invited expert about this?

Dr. Julie Daniels: I guess I'm trying to distinguish that this is -- I mean, about something separate from surveillance, correct?

Dr. Susan Daniels: Changes in prevalence -- so, I think it's surveillance.

Dr. Rice: Yeah. I think this is talking about the folks that aren't part of the ADDM Network that want to do some sort of autism surveillance. And can they get help in doing that? And so, Autism Speaks through the global Autism in Public Health initiatives provides some of that support, and then CDC, we don't have any mechanism for a formal non-ADDM surveillance program. But we do provide some technical assistance and try to respond to requests and share information as they come in, whether it's from other states or other countries.

So there's no budget reflected to that because there's no -- it's just more of a personnel duty than it is an actual program.

Dr. Susan Daniels: Good. So if there is nothing else on that, let's move on to the next one.

7K: “Encourage programs and funding mechanisms that expand the research workforce, enhance interdisciplinary research training, and recruit early-career scientists into the ASD field by 2013.”

And the last time this Group met, they concluded that the recommended budget was met and exceeded. And the Group asked for specific information about NIH projects for training and fellowship grants. And so we've provided the information here.

There was also a request that we examine the portfolio to separate out any training for people who are in the services workforce and not in the research and scientific workforce, and there were four projects, and they were pulled out. And we will have to talk with the funders to ensure that that's okay with them. But we'll let them know the Committee requested that we pull those out of this category.

But it was a very small change in funding. It was $1 million or so total. And the numbers for the NIH-supported training and fellowship grants that were coded according to the science; that was a much larger number. And that is not even reflected in the $24 million here.

So does the Group then feel that this objective has been met? Are there ongoing concerns about certain areas that might not be addressed the way they need to be?

[Pause]

And we don't have Dr. Insel on the call, but he had wanted us to pull up these numbers, and we have them here. So tentatively, then, we're going to say that this one looks like it's been largely met, unless in the larger group setting, if people have other comments about areas that still need attention.

Ms. Singer: And I think that we have to be careful when we say that the objective has been met. You know, it's not done. That I think it's fine to say that over the reporting period, more resource was devoted to training and developing the workforce, but that it has to continue, not that we can cross it off the list.

Dr. Susan Daniels: Yeah. And this is --

Mr. Hall: I support that.

Dr. Rice: Yeah. That's a really important point. And I think also, maybe for future needs, thinking about, is there a specific way we need to target this more? And then this is the research workforce in general, but then looking at the distribution of the research that's done across the whole portfolio, you know, we've talked a lot about the limited work being done on Questions 4, 5, and 6, in particular.

And a suggestion would be to target this in the future with an emphasis on research workforce in terms of services, service-based intervention, research, and across the lifespan.

Mr. Hall: If I could add, you know, our two cents on this, you know, we've been making a concerted effort to go out to omics communities, imaging communities to show that we have all this data that they could use to really expand, you know, their hypotheses that they may have. That they don't have to, you know, go out and get their preliminary data, that those types of things exist and is available and gives them a leg up by coming into autism and, you know, looking to, you know, start careers in autism based upon the amount of data that's available for secondary analysis.

Dr. Susan Daniels: And in terms of NIH, we did provide numbers for 2008 by $0.1 million versus 2012, $7.7 million, so showing the trend there. But the point is well taken that there might be some specific areas that the Committee would want to call out if they want to continue to keep this objective active in the Plan.

7L: "Expand the number of ADDM sites in order to conduct ASD surveillance in children and adults, conduct complementary direct screening to inform completeness of ongoing surveillance, and expand efforts to include autism subtypes by 2015."

And we talked with Cathy to get some

information on this and provided it here in the table -- that the recommended budget was partially met. But the full funding of ADDM sites is reflected in 7I. So that has an impact on the funding. And probably, in reality, parts of the funding for the ADDMs address both of these objectives.

But then, since we count everything in one objective at a time, we don't double-count anything; it has to have one place to land.

Dr. Rice: And I think similar to the conversation we had about the intent of this was supplement, not the core activities. And so this funding does represent the actual supplement.

Dr. Susan Daniels: Okay. So there's some information here about the supplements that have been provided, with an emphasis that they are limited, but they do address some of the concerns or the goals that were intended in this objective, adding younger populations and also looking at older populations, but that further work is needed.

And then, there was also a comment that, in terms of the subtypes, that with the changes in the *DSM* that the focus might be more appropriate on characteristics of children and adults rather than on subtype.

Cathy, do you have any other comments about this one and where it is and where it needs to go?

Dr. Rice: I think this is a good description of where it is. But certainly, others can add in that have experience with this. And really, very -- there's really been nothing addressing the adult issue. So that's certainly still an important need.

Dr. Julie Daniels: Yeah. And that's the only thing I was going to add, was that the adult piece of this is absent. I do know there is some work toward doing this in adults but not under the CDC.

Dr. Susan Daniels: Where is that work happening?

Dr. Julie Daniels: I think it was NIH funding, but it's happening here at UNC. [Inaudible comment]

It's not that it's sensitive. It's the follow-up of the TEACCH -- people who went through TEACCH years and years and years ago and trying to reassemble what has happened across their life course. So it's a little different.

Dr. Susan Daniels: Okay.

Dr. Julie Daniels: Laura Klinger and Joe Piven have that grant.

Dr. Susan Daniels: And that's from Autism Speaks?

Dr. Julie Daniels: I don't know; maybe. I can't remember the funding agency.

Dr. Susan Daniels: I'm wondering if it might be in the number that's here or not. Oh, but if it's brand new, it wouldn't be if it's 2013.

Dr. Julie Daniels: Yeah. I think it probably is.

Dr. Susan Daniels: Okay.

Dr. Julie Daniels: So yeah. I think that the surveillance of adults is still lacking.

Dr. Susan Daniels: Okay.

Dr. Durkin: I know that Paul Shattuck -- he's now at Drexel University -- has done a lot of work in this area. And I think he has NIH or NIMH funding.

Dr. Susan Daniels: To do surveillance in adults?

Dr. Durkin: Well, he does -- I believe he's following -- I don't know. You know, it might be a case worth looking at, to what extent is there surveillance.

Dr. Rice: I think a key question is --

Dr. Law: He uses a lot of – there are databases that have a lot of information about services provided to adults who have disabilities, to use those large national data sets. But I don't think it would qualify as surveillance, because, you know, the loss of subjects and the -- I mean, it would be like the equivalent of -- my understanding is it would be the equivalent of one of using, say, Medicare data, or Medicaid data.

Dr. Susan Daniels: Right. And we do have -- all of NIH's funding is reflected here. We have all the projects that were with NIH. And we do know that Paul Shattuck -- I think he's mostly in Question 5.

Dr. Rice: And I think that, well, the question here is what is meant by surveillance, because of some of the challenges with getting a true population estimate if we're just talking about prevalence versus population characteristics.

So there is some work like the studies that were mentioned. In terms of following up the particular groups, Utah has followed up their early epi cohort as well, and maybe that's something that should be considered here. I think Autism Speaks funded that.

And so those studies get part of the way in terms of looking at particular populations and the characteristics of those individuals as adults, but not the broader population view of prevalence, distribution of characteristic functioning, but the things that would be more complete. And that's still a big gap.

So you know, I think we didn't put these things like the Shattuck studies and everything because they are more in Question 6. But it may be worth noting here.

Dr. Susan Daniels: We can note that. And that's something that we've been doing throughout this process, because there are projects that had a best fit in another part of the Plan. But if they're relevant to another objective, we've just been noting that.

So, the Utah study, it's not here; it's somewhere else. We do have follow-up Autism Speaks projects. We have a number of different funders that contributed to these numbers. So we have most of the major ones. Are there any other comments on this?

Okay. Let's move on to Promising Practices, 7M: "Support 10 'Promising Practices' papers that describe innovative and successful services and supports being implemented in communities that benefit the full spectrum of people with ASD, which can be replicated in other communities, by 2015."

And CMS initially had a project for this back in 2008 or '9. And the Committee wanted to see more of this done. And I have reached out to CMS to find out what the status is and was not able to find any papers, new papers that have come out since 2009, but have asked for additional information about whether this is still ongoing or not.

And if it's not, whether this is just not a top priority at this point, or if other work has superseded it. So we will try to get that information from them.

But as far as we’ve been able to tell, there have been no new papers. So this didn't move forward.

Ms. Singer: Ellen Blackwell might be a good person to reach out to on this. She is the one who really pushed for this in the Strategic Plan. And I know she was very involved in that. And she might know the status of the project at CMS.

Dr. Susan Daniels: Yes. She wasn't able to give me the information. So I've reached out to the project officer --

Ms. Singer: Okay.

Dr. Susan Daniels: -- that is managing the project that was the manager of this project back in 2009, to find out what happened and have not yet heard back from them. But as far as I know, nothing has happened here.

Does this Group have any feel for whether this seems like something that -- for example, if CMS has not pursued doing more of these, whether this should remain a priority? Or if this is a lesser priority compared to other things that are ongoing?

[Pause]

Mr. Hall: I think you should leave it in here. I think there are -- you know, we just talked about the adults, you know, and what practices are being done there. I know Connie Kasari and Helen Tager-Flusberg just published on minimally verbal and, you know, how to handle those types of subjects in research.

I would think things like wandering and elopement, you know, are important items. And you know, I think this stuff already exists. It's just a matter of, you know, organizing it.

Dr. Susan Daniels: Right. So this was talking about a very specific mechanism of publishing issue brief on each [Inaudible comment] versus there probably is a lot of information out in the community already, put out by various advocacy organizations and states and so forth.

Mr. Hall: Yeah. Yeah.

Dr. Susan Daniels: So there might be a lot of uncataloged information about practices. In fact, I'm guessing that most states have put out something.

And the State of the States projects will probably have a lot of this type of information in it, I'm guessing. But I'll try to confirm that with CMS.

Ms. Singer: I would be happy to see this one go. I mean, I'm not even certain that these Promising Practice briefs are research practices. So you know, I never really understood how this was different than the State of the States. And I asked Donna to explain several times how it was, and I really still don't know. So I mean, when we have to go through and prioritize these objectives this year, as far as I'm concerned, this one will be pretty low on the list.

Dr. Susan Daniels: Okay. What we can try to do is also to find out if the intent of this has been met -- basically if information about successful services and supports methods are being disseminated -- and try to find some examples of how those are being disseminated.

And if the spirit of this is being met, maybe not through a Promising Practices paper, but through other means, to be able to document that.

So let's move on to 7N: “Enhance networks of clinical research sites offering clinical care in real-world settings that can collect and coordinate standardized and comprehensive diagnostic, biological, medical, and treatment history data that would provide a platform for conducting comparative effectiveness research and clinical trials of novel autism treatments by 2012.”

And this one, the Group felt the recommended budget had been met and wanted to discuss on this call the value of the ATN and whether the ATN has been useful to researchers.

So does anyone on this call have comments about that? And perhaps that question might also be useful to bring up in the larger group next Friday.

Mr. Hall: I mean, my comment on the ATN is, you know, we have this 90 percent of all human subjects research shared. And the ATN, as far as I know, is not broadly shared. So you know, this is a significant funding amount that is available. But it's -- I guess it's not as broad as some of the other repositories that we have out there.

Dr. Susan Daniels: Anything else? Anybody else have any comments about this? And I guess maybe Thomas might have comments on this as well when he joins us next Friday.

Alright, let's move to 70 --

Dr. Law: Well, I --

Dr. Susan Daniels: Oh, sorry. Paul, do you have any?

Dr. Law: My comment would be that I think it's making a lot of progress toward meeting [Inaudible comment] on the development of clinical guidelines, which is what it was supposed to be doing at its beginning. But it took a while to become, you know, kind of focused and practicality as opposed to just sort of collecting data, lots and lots of data that was not very directed, I think, at first.

Dr. Susan Daniels: Okay.

Dr. Law: But I think, it's a very good thing to being you, you know, clinical guideline oriented in recent years.

Dr. Susan Daniels: Yes. In the IACC, we did hear a little bit about some of the clinical guidelines that have come out from the ATN. So we can make note of that.

Anything else before we go to 7O? And we're getting close to the end of this list. "Create an information resource for ASD researchers [the example is the PhenX Project] to share information to facilitate data sharing and standardization of methods across projects by 2013."

And I believe on the revised version that I sent out and that is posted on the Web, we have some information that Dan shared with us about NDAR efforts in this area. Dan, would you like to comment on that?

Mr. Hall: Well, certainly. I mean, we have a common subject identifier that is, you know, non-identifying and used broadly across most all U.S.-funded autism research. We do have an autism data standard that we are enforcing use of. And that's out there and available.

And we are now, as I discussed earlier, implementing these computational approaches, you know, to help standardize methods or look at variances across methods for, you know, complex experiments.

You know, so we got harmonization. But then there's the standardization of protocol, which is a much more difficult thing to do. So you know, that still is certainly out there in the Project PhenX, you know, identifying concepts and measures that are more consistently used. You know, there's definitely opportunity there.

Dr. Susan Daniels: And so, who do you think would play that kind of a role?

Mr. Hall: I mean it's the funding organizations. And to try to, you know, show commonality. And I think we're starting to do some of that with, you know, looking at concepts across measures, because right now, if you look at NDAR, there are 350 measures out there. And you know, do we need 350 measures across 45,000 data elements?

Potentially not.

So you know, I think somebody needs to look at this. And it's probably, you know, the NIH, to lead the way in really looking at what are the best opportunities. This is going to take a while to resolve. This is not something that you're going to resolve right away. And dictating approaches is potentially quite damaging.

So, and you've got to go slow on this. But I think there's opportunity to share leadership in this area.

Dr. Susan Daniels: Great. Thank you.

Do others have comments on this? Alright, if there are no other comments, let's move on to the last objective, 7P: "Provide resources to centers or facilities that develop promising vertebrate and invertebrate model systems and make these models more easily available or expand the utility of current model systems and support new approaches to develop high-throughput screening technologies to evaluate the validity of model systems by 2013."

And the Group last time felt that the

recommended budget had been met and that there are mechanisms for sharing organisms. And the question came up, is there a continuing need for special support for those?

And Thomas Lehner isn't here, but are any of you -- would you like to comment on this? It talks about models, that if the -- and the sharing of models.

Ms. Singer: So, I think this is another one where there's been a lot accomplished, but we're not really ready to say it's done, we don't need any more models.

The Simons Foundation has a big funding mechanism that specifically targeted this. It's ongoing. So when you look back at the reporting period, you think, yes, we accomplished this goal. But again, it's an issue of not wanting to say we don't have to do it anymore.

Mr. Hall: Yeah, I agree. I mean, I think a lot of this is being accomplished. It's hard to show that because, you know, these things are shared through different, you know, mechanisms than, you know, what we have oversight over.

Dr. Susan Daniels: Are there specific, any kind of actions that you can think or future steps that would really help this? Anything different than what's already being done that needs to be done? A way of refining it to make it a little more targeted?

This is one that I don't know if we -- we may have more input at the workshop because there might be more people around the table who actively work with animal models who can talk about this.

So if not, why don't we save that discussion maybe for the workshop then, if we might not have all the people that we might want at the table for this.

So you've gotten through the objectives. And now you, hopefully, have a basis to be able to discuss, at least for a short time here, what the progress has been, in your opinion, toward meeting the aspirational goal: "Develop and support infrastructure and surveillance systems that advance the speed, efficacy, and dissemination of autism research."

So how do you all feel we've done in the past

5 years toward this aspirational goal? What are the glaring gaps that might still be there? What are the accomplishments? Thoughts?

Dr. Durkin: Well, this is Maureen Durkin. I'm not sure -- because I don't know the background, I'm not sure exactly where this came from or what you were getting at. But I do think that we could be doing a lot better at surveillance in terms of developing more efficient -- you know, constantly improving the efficiency and speed on it.

But that would take funding and more effort. And if current -- the current surveillance system is just barely able to accomplish its goals, immediate goals. And there's no extra resources for investing in improvement is my view.

The other thing, I think, in terms of efficacy, I think that the glaring omission, actually, in this whole agenda and what we've talked about today, is what are the disparities? You know, sort of, who gets identified as having autism? And who gets access to services and things like that?

And we don't really have a good way of

monitoring that and getting it onto the national agenda.

I also think that there's much more need for -- the more we learn about autism and the epidemic or the epidemiology of it, the rest is -- I think we realize that it's not one of these disorders that the more we develop surveillance, we see the rates going down. In fact, it's the opposite.

And I think it's going to be awhile before we see rates, we have the interventions in place to bring about primary prevention.

And in the meantime, there are a lot of children and adults with autism who aren't -- we're not paying much attention to their functional status. We're not monitoring that in any way in terms of the surveillance system. Or in terms of their discrimination, health disparities, lack of access to employment, and that kind of thing that we should be paying more attention to.

I think our whole surveillance effort is focused more on just how to monitor the number of cases, and with the thought that this would bring about primary prevention. And that's not happening in any rapid fashion.

So I think we need to pay more attention to these other aspects.

Dr. Susan Daniels: So just as a comment on disparity issues, but the two specific issues you mentioned, identification and services, those are covered in other chapters of the Strategic Plan. And this is one of the issues with overlap. There is overlap between the different topics.

And so the issue of disparities and identification is in Question 1. And disparities and access to services is in Question 5. So it is being covered in the Strategic Plan but not in Question 7. But if there are specific surveillance-related issues with disparities that you think, you know, belong here, that would be great to hear more about that.

Dr. Rice: This is Cathy. I would add that, I think, looking at some of the objectives in the other questions is important, too, for surveillance in the sense of looking at health needs and service needs, as well.

But I think in this Question 7, the intent and the focus really was on just the basic prevalence, not so much for the idea that prevalence or understanding that leads to primary prevention, but just that describing the population.

But so thinking about which of those gaps go specifically here, I think the point about -- I would take looking back at some of the other questions to see about more of the service-based needs. But I don't think we really have a good -- and it reflected somewhere about the issue of monitoring who gets identified, as well as what is the impact of that identification. Do those individuals actually get linked to services in a timely way based on identification?

And maybe that one, I'm thinking, over the whole Plan, I don't think that's something that is reflected anywhere else.

Dr. Susan Daniels: Okay.

Dr. Rice: I think it would be good, with the comment Maureen made, to eyeball and look over this whole Group of us, to look over the rest of the Plan and see, are some of those gaps represented elsewhere? Or do we need to think about ways to put them here?

Dr. Susan Daniels: And, Maureen, this is Susan. Just to clarify a little bit, you mentioned the need for more funding for surveillance. Is it more funding for anything specific, like anything new or different than what is being funded? Or just more funding for what's already being funded?

Dr. Durkin: Well, I think funding specifically to develop in a more efficient way, you know, the performing surveillance and evaluating how effective it is. And then I'm sure, with improved electronic data, electronic medical records and everything, I'm sure there have got to be better ways, as we move forward.

But there really hasn't been any innovation in this area in a long time, I think, in this country. And this is a glaring omission, in my view. And you can't do it within the existing funds, because those are just dedicated to performing the current methodology.

Dr. Julie Daniels: Yeah. I have been thinking the same thing, is that the increased electronic access to information, we should be thinking forwardly about how to make better use of that data and validate what we're doing against it so that we could, potentially, move toward -- less toward the shoe-leather approach that we're doing now, if it becomes more efficient to do it another way. And that's going to take some investigative work.

Mr. Hall: You know, my -- you know, I guess to dovetail on that, you know, as far as aspirational goals, you know, I think we really need to get to the point where everyone's results are shared, you know, and the data that's, you know, being federally funded, that the really changing attitudes that, "Oh, this is, you know, something that I was forced to do," to, "This is critical to progress in the field," to changing attitudes toward data sharing.

And not only just the raw data, but really -- and publications are starting to come online with this where, you know, you have to share genetics results data in a repository. You know, these types -- this goes across all types of human subjects research.

Whether it's task based, fMRI, eye tracking, omics, or clinical trials, you know, the attitudes, you know, just need to change to improve the quality of data sharing. And really, how that's done is not that we have all the raw data, but we really, you know, don't have the results publications for simple corroboration. And we can get there. I mean, the infrastructure is in place to do that.

Dr. Julie Daniels: Yeah. I agree, too. I think that the challenge with surveillance data is the lack of a form of consent. It makes it challenging from that perspective. And that's an important caveat for that.

Dr. Law: This is Paul. And I'm remembering back to the days where I [Inaudible comment] evaluated Johns Hopkins surveillance, which comes from RSV and the hospital. But to me, it seems like the surveillance systems have the purpose of leading to some clinically actionable, you know -- some clinical action.

And then there are surveillance systems that are designed to determine prevalence. And the CDC system, I never really thought of it as a system that led to individual-level clinical actions. It causes all of us in society to respond to the problem of providing prevalence data, but it's not terribly useful information at the individual level, especially since it's designed for 80-year-olds.

So Maureen, I was just wondering, like which type -- it seems to me like you were running a surveillance that's aimed more at [Inaudible comment] better health outcomes --

Dr. Durkin: No, I didn't mean it -- I agree with you totally that this is population level and it's not individual developmental surveillance or anything like that.

But I'll just give you an example. We're also conducting surveillance of cerebral palsy within the ADDM Network. And we've been able to innovate in that recently and add functional measures so that we can report not just whether a child is, yes, no, they have CP or not, but also something about the functional status. And that helps with monitoring over time as to whether we're making improvements or not.

I know in autism, it's becoming more important, with the new *DSM-5*, I think there's more prominence given to function. And when we think about looking at the results from Korea recently with the prevalence of, you know, nearly 3 percent, and yet the functional status that most of those children seem to be in, they didn't seem to have any functional impairment.

So I think it's important to incorporate that information into public health surveillance, if we can, in this area.

Dr. Law: I agree. I can remember we made the comment about useful electronic health information. But even that's -- one of the biggest weaknesses, I think, of the CDC methodologies for surveillance is that it depends on the health systems and the school systems for getting to information.

And when you enter into the world of electronic health records in this country, the disparities in our experiences with our electronic health records, it gets the positive and what doesn’t depending on what doctors are saying, you know, what situation, what time of day.

It really adds a whole lot of extra biases to the situation. But anyway.

Dr. Rice: Yeah. There's a few comments that I would add, is just that, one, I think we make a lot of statements about disparities that we need better data on. So that's one issue, I think, about really understanding what we're talking about.

Because if we're talking about identified diagnoses in autism, you do see gaps. But when you look at some of the data sets that are more about proportion of who gets screened or the types of services, you don't always see the same disparities that we think that are there, that often those that are on publicly supported programs are getting earlier and more service in some areas.

And so I think we have to be careful about blanket statements. But that this brings up the issue and that we -- that may be most appropriate again in kind of the services monitoring, or whether that's here, we need to talk about an infrastructure for really understanding both functional impact and service access, the needs across the lifespan.

And whether that's the same as basic population surveillance, you could argue it is and it isn't. You know, there are some aspects that could be captured. But certain things like functioning, in the case of autism, is much more challenging then when we're talking about gross motor functioning in CP, because that's one domain.

And we have areas where we look at one domain and functioning in autism. You can look at level of language. You can look at intellectual functioning. You can look at adapted behavior scores. But autism is not defined by one easy function level.

And so hopefully, we have opportunities with some of the guidance and changes within *DSM* to add those types, you know, come up with ways. But they still really need to be tested. We're still at the level of basic research, of understanding how to capture functioning within autism.

So there are some needs that we're talking about here that are part of the service infrastructure, some that are part of basic research and understanding function, and then some are about having ongoing data and monitoring systems that not only capture the population of who is affected with autism, ideally across the lifespan, but also some of the key characteristics and needs and access to services of that community.

So that's a lot to parse out. And so I'm trying to think about, what is specific to this infrastructure question that's really key here? And how -- and is that captured in any of the, you know, other objectives that may need to be tweaked in the future?

So you know, we have objectives like, let's see here, 7A -- talking about merging existing databases to allow for tracking people with ASD across health care, education, and social services. I mean, that's a real specific, practical way that we could get some of the information we need. And do we call that a surveillance system or not?

And so you know, I guess I would just ask us to be a little more specific about what are we talking about? Are we talking about redefining surveillance really to be a service-based and functioning assessment? Or are we talking about just the basic population sets? Or are we talking about something different from 7A, to be more specific about that?

I don't know if any of that made sense.

Dr. Julie Daniels: Well, maybe one of a sort of a shorter term goal is to identify the trackable features that we could potentially expand to enhance our current surveillance protocols. Because I think that there's a lot of data that isn't captured because of limitations on time and resources and ability to standardize it.

But there probably are some opportunities that we could capitalize on as we spend some time constructing and thinking about that.

[Pause]

Dr. Susan Daniels: Other comments on the aspirational goal and where we are with it?

Mr. Hall: You know, I would say, in 5 years there's been tremendous progress, at least in this area. But you know, as Tom said in the beginning, what do we need over the next 5 years, you know? And you know, I think we've got to put those -- you know, those recommendations out there. I think it's up to us to define what those objectives need to be.

And you know, as Alison pointed out, it's not that these things are coming off the tables and were thrown out and we've done all the green ones. You know, what's the next step? And you know, I guess that's what our objective is for next week?

Dr. Susan Daniels: Exactly. So we will want to talk about what those next steps are. And you know, with some of these where a lot of progress has been made, I think the Committee is going to want to think about next steps and not just saying let's keep on keeping on.

I mean, we do want to maintain progress, but you always want to set a goal that's further ahead for something to strive for. So I would imagine that the Committee will want to hear some ideas for future direction.

Mr. Hall: Susan, should we be prepared with --

Dr. Susan Daniels: Yeah. So that would be something that you can do to prepare for the workshop next Friday. And so that was part of the goal of this call, to get you to thinking through the specific objectives in more detail, and then you'll have something to use as you think about, you know, possible future directions.

Ms. Singer: I just want to add that I think it's important for us when we're writing the introduction to this section to be able to also identify any changes in infrastructure that were critical to the fields that were not reflected in the objectives.

So I will throw one out. I think the database that OARC created that has all of the funded studies, with the name of the funder, the name of the PI, the university, the title. I mean, that is in and of itself a valuable piece of infrastructure. So if there are other things that have happened that are not captured in the objectives, I think we want to know about that, too.

Dr. Susan Daniels: We definitely do. And we want to -- we'll try to note that throughout the notes that we give back to you. Thank you for bringing that one up. I think the OARC has tried to put together something. And now that we have 5 years worth of data, the last 2 years haven't been inputted into the database yet. But it's a publicly acceptable way for people to be able to access data freely and do their own analysis of what's happening --

Ms. Singer: None of the other disease advocacy groups have anything like that. When I show that to them, they are floored. They're all going to ask for it.

Dr. Susan Daniels: And we've been getting requests.

[Pause]

Anything else? Any other thoughts about the aspirational goal? And we will have more time to discuss that in the next -- in the workshop. During the workshop, the workshop is going to be divided according to the six -- well, seven -- questions, but two of the questions -- actually, no. We have seven separate question periods to talk about each. But they're fairly short. They're under 1 hour. Just because, with an 8-1/2-hour day, there wasn't a way to fit in a lot more and be able to get people in and out on the same day.

So we will have to fairly concise with certain things. And if needed, we could always arrange a call afterward.

But we look forward to having you all there. And you'll be receiving some instruction about that. We'll be sending out more guidance and information, and our team will go ahead and update this table, and then provide that back to you as a further summary of what you've discussed and what your findings are.

And any questions that have come up here that you wanted us to follow up on, our team will follow up on those items and try to get that information together for next week's workshop.

Are there any questions that anyone has before we adjourn our meeting?

Well, thank you so much for joining us. We especially extend our appreciation to the invited experts who have joined us and to the IACC members for continuing this important work. And we really appreciate you being here.

And we look forward to seeing many of you or hearing you over the phone next Friday. And that workshop is open to the public. Anyone who is interested can go to the IACC Web site and, under Meetings and Events, you'll find all the information about those upcoming workshops.

Thanks, and we're adjourned.

(Whereupon, the Strategic Plan Question 7 Planning Group was adjourned.)