

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

FULL COMMITTEE MEETING

FRIDAY, JULY 27, 2012

The meeting convened via teleconference and webinar at 10:00 a.m., Thomas Insel, Chair, presiding.

PARTICIPANTS:

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

SUSAN DANIELS, Ph.D., *Executive Secretary*, Office of Autism Research Coordination (OARC), National Institute of Mental Health (NIMH)

IDIL ABDULL, Somali American Autism Foundation

ANSHU BATRA, M.D., Our Special Kids

JAMES BATTEY, M.D., Ph.D., National Institute on Deafness and Other Communication Disorders (NIDCD)

LINDA BIRNBAUM, Ph.D., National Institute of Environmental Health Sciences (NIEHS)

COLEEN BOYLE, Ph.D., M.S. Hyg., Centers for Disease Control and Prevention (CDC)

**NEAL R. GROSS**

COURT REPORTERS AND TRANSCRIBERS

1323 RHODE ISLAND AVE., N.W.

WASHINGTON, D.C. 20005-3701

(202) 234-4433

[www.nealrgross.com](http://www.nealrgross.com)

## PARTICIPANTS (continued):

NOAH BRITTON, M.A., Bunker Hill Community  
College

SALLY BURTON-HOYLE, Ed.D., Eastern Michigan  
University

MATTHEW CAREY, Ph.D., Left Brain Right Brain

DENNIS CHOI, M.D., Ph.D., Simons Foundation

JOSE CORDERO, M.D., M.P.H., University of  
Puerto Rico

JAN CRANDY, Nevada Commission on Autism  
Spectrum Disorders

GERALDINE DAWSON, Ph.D., Autism Speaks

DENISE DOUGHERTY, Ph.D., Agency for  
Healthcare Research and Quality (AHRQ)

TIFFANY FARCHIONE, M.D., U.S. Food and Drug  
Administration (FDA)

ALICE KAU, Ph.D., *Eunice Kennedy Shriver*  
National Institute for Child Health and  
Human Development (NICHD) (representing  
Alan Guttmacher, M.D.)

WALTER KOROSHETZ, M.D., National Institute of  
Neurological Disorders and Stroke  
(NINDS)

CINDY LAWLER, Ph.D., National Institute of  
Environmental Health Sciences  
(NIEHS) (representing Linda Birnbaum,  
Ph.D.)

SHARON LEWIS, Administration for Community  
Living

## PARTICIPANTS (continued):

SHUI-LIN NIU, Ph.D., Department of Defense  
(DOD) (representing Donna Kimbark, Ph.D.)

DAVID MANDELL, Sc.D., University of  
Pennsylvania

JOHN O'BRIEN, M.A., Centers for Medicare &  
Medicaid Services (CMS)

LYN REDWOOD, RN, M.S.N., Coalition for  
SafeMinds

SCOTT MICHAEL ROBERTSON, M.H.C.I., The  
Autistic Self Advocacy Network (ASAN)

ALISON TEPPER SINGER, M.B.A., Autism Science  
Foundation

LARRY WEXLER, Ed.D., U.S. Department of  
Education (representing Alexa Posny,  
Ph.D.)

TABLE OF CONTENTS

Roll Call and Opening Remarks	
Dr. Thomas Insel.....	5
Orientation Items	
Dr. Susan Daniels.....	7
IACC Business	
Dr. Thomas Insel and	
Dr. Susan Daniels.....	21
Subcommittee Establishment.....	21
Strategic Planning.....	60
Summary of Advances.....	75
Portfolio Analysis.....	92
Public Comments Discussion.....	124
Closing Remarks.....	163
Adjournment.....	167

## PROCEEDINGS

(10:04 a.m.)

Dr. Insel: Thank you. Good morning, everybody. We're ready to start for this conference call and webinar for the Interagency Autism Coordinating Committee and we have a number of people here in the room at NIH.

The way this is setup is that, those of you who are on the committee are able to participate as regular members and to converse with us, and we also have a number of people from the public listening in who will be on listen-only mode.

So we have quite a bit of business to take care of today that just didn't get completed and what was a too ambitious agenda for our first meeting a couple of weeks ago and this is really kind of a make-up session to complete what didn't get done there.

But I want to start by just making sure we know who's on the call, so I'm going

to turn this over to Susan to go through the roll call and find out who's here.

Dr. Daniels: Good morning. I'd like to go through the roll call for the IACC.

If you could just indicate to me that you're on the line or if you are an alternate serving for a federal member that you're on the line.

That would be appreciated.

(Roll call.)

Dr. Insel: Well, we certainly have a quorum, so we can go ahead and get started. And what we thought we'd do today, as you can see from the agenda in front of you, is to go back through some of the orientation items, Susan's going to take us through those, and then get to the business that did not get completed the last time.

Dr. Burton-Hoyle: And this is Sally Burton-Hoyle and I had to get a different phone, so I'm in. Thank you.

Dr. Daniels: Great.

Dr. Insel: Okay. Good. We knew

you were here earlier.

Dr. Burton-Hoyle: Okay. Thank you.

Dr. Insel: We knew you were trying to get back in.

Dr. Daniels: Any members who joined us a little bit late, feel free to mention that you're on the call.

Dr. Insel: And, Geri, we understand you have to leave by noon, so we'll try to move quickly and finish as much of our business as possible.

Dr. Dawson: Thank you.

Dr. Insel: Okay. Susan, let me turn this over to you and you can take us through on the orientation piece.

Dr. Daniels: Okay. All right. Great. So I just want to take you through a few quick items here on orientation. There's more that we can share via email of more esoteric issues related to service on the committee, but some of the general ones that

would be of interest to everyone, hopefully, are just to briefly reiterate the IACC statutory responsibilities that the committee has.

These responsibilities include advising HHS Secretary Sebelius on matters related to autism, to establish an autism list of research priorities, and so we do that through the IACC's strategic plan for ASD research and any kinds of updates to the issue for that.

The IACC is to communicate advances in the field for the public, for Congress, for other audiences for the federal agencies and private organizations, and we do this through the IACC Summary of Advances in ASD research publication that we do each year.

And the IACC is to monitor federal activities and analyze research trends. And this activity actually has been expanded to include private funders, because we have so many private funders as a part of this effort



and we recognize how important it is to get everyone together working on this.

And so the IACC issues an annual ASD research portfolio analysis in addition to other products that we have done, including this year, our publications analysis to help the IACC monitor those activities.

I wanted to give members just a brief introduction to the office that I run, the Office of Autism Research Coordination, which is housed at the NIH, but serves this committee. This is a list on the webinar for those of you who are logged in to the webinar, but you can see the staff that we have.

It's a small staff, but we carry out all the different functions that we need to to help the committee do its work. On the next slide I've just briefly outlined a few items that we assist with, including planning, meetings, conferences, and other venues for interaction with the public.

Assisting the IACC in its

strategic planning and research monitoring activities, and that is all conducting analyses, preparing documents and reports. We also help the IACC gather public input on any issues related ASD, and we communicate information about the IACC and federal research activities to Congress, government agencies, and the public.

Dr. Insel: Maybe before we go on, let's just see, are there any questions about what -- because this is our team and they serve you, and their role is, really, as a way of helping the IACC do its business.

It's a small group. They're very, as you mentioned the last time, very committed and you're likely to get emails from them at any of the 24 hours in the day, but we want to make sure you knew who was involved. You got a series of publications at the last meeting, those, entirely, were based on the hard work of the team that's on that list. Any questions? Okay. Let's go on.

Dr. Daniels: Yes, and by the way, just for the webinar, for anyone who wanted to be on the webinar, on our Web site, on the meetings and events page of the IACC Web site, there's a link and you have to click on that link and register to be involved in the webinar, and it automatically will help you download GoToWebinar and then you'll get into this webinar so you can see all these slides.

We also will post the slides after the meeting. I wanted to go over some really brief points about IACC meetings that might be helpful to the committee. The Combating Autism Act and the Combating Autism Reauthorization Act require a minimum of two meetings of the full IACC per year; however, we have been having many more meetings than this in the past several years.

Dr. Birnbaum: Excuse me.

Dr. Daniels: Yes.

Dr. Birnbaum: Hey, this is Linda Birnbaum. I've been trying to get in for the

last ten minutes, but I finally got in.

Dr. Daniels: Yes? Oh, thank you.

Dr. Birnbaum: Okay.

Dr. Daniels: So we'll put you down. Thank you for letting us know.

Dr. Insel: All right. Cindy is already on, Linda.

Dr. Daniels: I think Cindy will be listening and not speaking as long as I can be on. I have an 11 o'clock talk I have to give and then she'll -- so we'll be playing tag.

Dr. Insel: Okay. Good to have you. Thanks for joining.

Dr. Daniels: Thank you.

Dr. Birnbaum: Okay.

Dr. Daniels: In the past, the IACC has had an average of, usually, six full committee meetings per year plus around eight to ten other kinds of meetings, phone calls, the subcommittees convene workshops, et cetera. So this committee does work hard and

has done a lot in the past, and we expect that they will, with all the ambition and vigor that they have, want to be meeting frequently also to work on the many important issues.

All the full committee, subcommittee meetings, and workshops, et cetera, are open to the public. We make them accessible by phone, webcast, or webinar. Meetings for substantive items that are discussed must be announced in the federal register, which requires that our office put in a 30-day lead time to get a federal register notice issued.

And so just keep that in mind that we can't normally have meetings at the drop of a hat and have them -- in this case, we got an emergency exception to have the meeting, but we can't make every meeting an emergency. So we do need some lead time to plan the meetings.

In addition, there are many new federal regulations about meetings that have

just come up in the last few months that require additional approvals before we can do in-person meetings, so that also has added significantly to what we're anticipating will be the needed lead time.

So today, on the call, we'll be talking with you about some proposed meeting scheduling so that we can start to get those approvals and get those approved, but in cases where we need to meet more quickly, we may have to do phone calls and webinars.

And also, the committee, of course, can let us know when you feel that a meeting is needed and that our office will work with you to balance the need for a meeting, what kind of meeting, with a budget and timing so that we can have these meetings be as effective as possible for you to get your work done.

Any questions about that?

Dr. Batra: Susan, this is Anshu Batra, I just wanted to let you know I was on.

Dr. Daniels: Okay. Thank you.

Dr. Cordero: Jose Cordero is on too.

Dr. Insel: Oh, great. Welcome.

Dr. Daniels: Thank you. All right. So on the next slide here, just wanted to let you all know. I'm sure most of you know that we have a Web site, the IACC Web site, and all the publications of the IACC and documents from every meeting, including slides, transcripts, minutes, and various other types of documents are available, plus we have access to other government documents and a list of outside events that may be of interest to the committee and to the public.

So please check out our Web site for lots of additional information. And just to let people know, final documents from IACC meetings are publicly available on our Web site or by request, so if there's something there that you want that you didn't see on the Web site, just write to our office and ask.

All right. So we're ready to move into the business --

Dr. Insel: Yes, so before we go on, other questions, or comments, or anything else around the background about how the committee operates and the supports available?

Ms. Redwood: Tom, this is Lyn. I have a question about the supports available.

Dr. Insel: Yes.

Ms. Redwood: I'm concerned that we may need to add additional staff. I'm worried about Susan going out on maternity leave and I've also noticed that, you know, we're getting emails at midnight on weekends, and I'm just wondering if that's something we need to assess.

Dr. Insel: Yes, it's a very good question and in addition to Susan's departure, Sara Dodson, who presented to us last time, will be finishing her fellowship in August, and she's been a huge part of the team.

So you may remember that in



previous years we had about nearly twice as many people in the office. So we will have to repopulate and we're talking a lot with Susan about how to do that right now. And also trying to make sure that the budget is stable enough to allow that as well.

Ms. Redwood: I was looking over the actual Act, Tom, and it says, under administrative support in Section 1 that, "The committee shall receive necessary and appropriate administrative support from the Secretary." So maybe we could cite that in terms of asking for more support.

Dr. Insel: We're in discussions with exactly that language very much in the forefront of the discussion with the Secretary's office right now.

Ms. Redwood: Great. Thank you.

Dr. Daniels: And, Lyn, for your benefit and everyone else on the committee, just so you know, I will be on maternity leave until the beginning of November; however, my

plan was to try to work part-time once the first few weeks are over and I can be back on my feet, to at least answer some emails, although, it might not be the complete rapid response that you're more used to.

And my staff are going to help keep me informed, so please, I will be sending you an email instructing you on how to get a hold of me if there's some sort of urgent business, and of course, I'm still going to be in the area and I will be helping with anything that's an urgent need, and if we have any meetings, I will make myself available to help plan those meetings.

Dr. Insel: We're also trying to reinforce the group a little bit in the short term from NIMH folks, so we're recognizing the next couple of months are going to be particularly difficult, but Susan has been working to do some recruitments and to get some additional people in.

So we're quite aware, but we are

going to need, again, to quote the statute, we're going to need some additional administrative support for the office from the Office of the Secretary. And I think they'll be responsive. Anything else? Other questions or issues?

Ms. Crandy: This is Jan Crandy. I have a question. For committee work, are we allowed to gather information and represent ourselves as members of this committee to gather information or are we only allowed to bring speakers to committee meetings to ask questions?

Dr. Daniels: I'm not sure what you mean by gather information. For example, if you talk with a constituent group when you come to a meeting you can certainly share what you've heard during our round robins. Is that what you're talking about?

Dr. Insel: And, Jan, you can represent yourself as a member of the IACC.

Ms. Crandy: So say we wanted to

find information out from a state, we could contact their HHS, or their Aging and Disabilities, and say we're a member of this committee, we'd like to have information about what services you provide.

Dr. Daniels: No, actually, so if you need to do something on behalf of the IACC, for example, you want to approach a federal agency, you need to work with me as the designated federal official for the committee and we have to get that approved by the committee before you can go and represent.

And it would most likely be in a group with other members of the IACC, but the IACC would have to endorse the activity. So you would need to bring it forward as a suggestion at a meeting and then we would need to make sure that the committee approved that activity.

And then I would need to be involved as the designated federal official.

Ms. Crandy: Okay. Thank you.

Dr. Insel: Other questions; thoughts? Okay. Let's go on then. We'll complete the business that didn't get finished at the previous meeting and probably the major thing was to setup the subcommittees. Just to rewind the tape a little bit, where we were at the last meeting was the discussion of the importance of having subcommittees as being the, kind of, primary working group of the IACC.

That's even more important now than in the previous version because the committee has grown so much. And we talked about having a science and a services subcommittee. We wanted to point out that, to the extent possible, we like the idea of following the previous format where we had two co-chairs, one federal and one non-federal, but we couldn't use the same subcommittees we had in the past because of the reauthorization, we have to setup new entities altogether.

The members are limited to all of you, but that everything we do in the subcommittees is covered by FACA, that Federal Advisory Committee Act policy, which we've talked a little bit about at the previous meeting, but FACA requires everything to be transparent and to be public.

So those subcommittee meetings would be held in the same way that the full committee meetings are, just as the meeting is today, that it's completely transparent. Any recommendations or any actions that come from subcommittees will need to be approved by the full committee.

So the subcommittee kind of does the work of putting together a recommendation or a proposal, but that has to get hammered out and discussed in full with the entire group. Right. So go ahead and say that.

Dr. Daniels: So I was just going to add. So the voting members are limited to IACC members, but if subcommittees feel that

they need to get expert advice from others they can invite in speakers or discussants, et cetera, to help provide advice, but those people can't vote with the committee. They can only provide the information.

Dr. Insel: And this has worked pretty well in the past. The way we've done most of the activities of the IACC has been through these smaller meetings, and that's included workshops and various other kinds of times when we've been able to convene experts, you know, where there's an area not represented on the full committee, or where there's some new opportunity that people want to hear about.

So I think those of us who were part of the previous version of the IACC felt like we wanted to continue to do this in much the same way, it's just now re-establishing the membership.

These were the two groups. We've added in safety in the services arena because

it's part of services and there's such an interest, at least there was in the previous IACC, in the issues relevant to safety.

And as you probably remember when we talked with the Secretary at the previous meeting, the safety issues were one of the areas in which we had specifically made recommendations to her. So it was one of the major action areas for the previous IACC. We thought that fit pretty well within the services arena.

When we talked about this at the previous meeting, we had the descriptions a little bit different than what you see in front of you now and that's because when we asked for volunteers everybody seemed to want to be on the science subcommittee, and we thought that was because the strategic plan was almost entirely within the science subcommittee.

What we thought we might do is to breakout the services-related issues in the



strategic plan and make sure that the services experts would help with the update of those. So the split now looks like this, I hope you have this in front of you, and these were just recommended areas.

There could be additional areas of coverage within these subcommittees, but it was one way of taking the broad expanse of issues for the IACC and just making them more tractable within these smaller working groups.

Any thoughts or comments about this?

Ms. Dougherty: This is Denise. I'm sorry. I'm trying to find the document that has these descriptions in it.

Dr. Insel: Okay.

Dr. Daniels: Are you on the webinar?

Ms. Dougherty: No, I'm not.

Dr. Insel: All right.

Ms. Dougherty: I'm on the phone.

Okay. Good. All right. I'll get on the webinar.

Dr. Daniels: There's some slides on the webinar, so if you go to our Web site on the webinar link you'll get them.

Ms. Dougherty: Okay.

Dr. Insel: And it's under the IACC business series and it's the second slide in from the title.

Ms. Dougherty: Thank you. Sorry about that.

Dr. Insel: Any other questions or comments?

Dr. Cordero: This is Jose Cordero. I have a question. Where would see the area of, let's say, interventions or research on strategies and the work for children or individuals with autism would fall, would that be under the science or be under this area of services and safety?

Dr. Insel: Let me see if I heard you right, the question is about where interventions would fall, which of the committees?

Dr. Cordero: Where research on potential interventions. Let's say that, like, the clinical trials like the one that's been done on the Denver Model and whether it works or not?

Dr. Insel: Right. That would be under the science subcommittee.

Dr. Cordero: Okay. And then if there are issues of implementing services, then that would go under services and safety.

Dr. Insel: Precisely. Yes. So we generally call that implementation science, so it's considered a robust area of science, but it is much more within the services domain because the kinds of questions and the kinds of studies done are much more in the community and deal with dissemination more than with the development of -- the R&D part of this.

Dr. Cordero: Okay. So that would be part of -- it's under the bullet of sciences research.

Dr. Insel: Yes.

Dr. Cordero: Okay.

Dr. Insel: So I think it doesn't, under services, mention dissemination research, but it should be there. It says et cetera with the idea that there will be things left out.

Dr. Cordero: Okay.

Ms. Redwood: Tom, this is Lyn. I'm also wondering if, under services and safety with regard to updating the strategic plan, we should also include question 7, which is infrastructure? There's things in there regarding State of the States assessments and other things that I think would also fall under services.

So it'd be great if they could also help in evaluating question 7.

Dr. Insel: Thank you. Yes, that was an oversight I think. There's a piece of 7 that clearly has to do with service provision, like the State of the States, and it's actually what we talked about last time

in the meeting when we had the discussion about Medicaid/Medicare issues.

That's entirely within the services arena, and yet, that's very much part of that infrastructure piece. So I think that should say 5, and 6, and 7.

Dr. Daniels: There's objectives and topics in other chapters, but one of the reasons that 7 was included on the science and surveillance piece, it's a little bit more related to science, but it's a mix.

Dr. Insel: Okay.

Dr. Daniels: And so, certainly, there's an opportunity for the appropriate expertise of each subcommittee could try writing pieces within their expertise area.

Ms. Dougherty: This is Denise. You know I'm interested in this, so what is the charge of the services committee other than providing a services research component to the updated strategic plan and what are the deliverables?

Dr. Insel: Right. So that would be the immediate issue, because it's due in December, and we would need a group to --

Ms. Dougherty: Okay.

Dr. Insel: -- come through and look at that. But going into 2013, the opportunity for each of the subcommittees is to create an agenda that fits the mission of the IACC and is consistent with the statute within the whole realm of, you know, remembering that we're an advisory committee, but this really is the working engine of the IACC going forward.

Ms. Dougherty: Okay.

Dr. Daniels: So you may be, as a subcommittee member, helping develop recommendations that could be made to the Secretary, having speakers come in to provide information and advice to the subcommittee that could then be shared with the full committee, so you may be involved in planning workshops, and that's in the slide that's

going to be done in terms of things the subcommittees could do.

Ms. Dougherty: Okay. Thank you.

Dr. Mandell: This is David Mandell. I wonder if it's worth, and maybe it's just a semantic issue that's not worth discussing today, but ultimately, it might behoove us to change the names of these committees if their mission has changed, because we now, sort of, have an artificial distinction between science and services, and yet, there's a lot of science that we're asking the services and safety committee to cover, as well as some other things.

And there are some things related, for instance, to infrastructure, that we're asking the science committee to cover that may not traditionally have been -- we may not, traditionally, have made that distinction.

Dr. Insel: Yes, these names are not in the statute. This is of our creation, so if you have a better idea, let's put it out

there.

Dr. Boyle: Yes, this is Coleen. I would second David's idea, as I get very confused when I look at the titles. When you actually look at the description it's a little bit clearer. So I mean, I might propose, rather than saying science, meaning that everything above it, it's not related to science, would be, maybe, biomedical and behavioral research.

For the second one, you know, services and policy research, something like that, related to the first one; something. A better description to know that we're really looking at the science and the research related to services and policies. And that includes things like translational studies, and evaluation studies, and cost studies, and policy studies.

Dr. Daniels: So then are you proposing biomedical and behavioral research, and services and safety policy research?



Dr. Boyle: Yes. I'm not sure I need to have the safety in there, but if other people feel strongly about that, that's great.

Ms. Lewis: This is Sharon, and I guess I just pose the question, because I know as a co-chair and a member of the safety and the services committee last time, certainly, the interest of the members was not to be only focused on research. And I think that under the charge of the committee, certainly, research is a critical, critical component and we want to talk about services research.

The coordination aspect of the committee also, you know, relates to the recommendation and the interests of the committee members beyond research, and I guess I'm wondering how, then, Coleen, you see that fitting together under if the two committees are both primarily focused on research?

Dr. Daniels: Well, Coleen's suggestion has policy in there --

Dr. Boyle: That's what I was

going to say, maybe we can say research and policy, Sharon.

Dr. Daniels: So services and safety, policy and research.

Ms. Dougherty: I kind of agree, though, with whoever spoke after Coleen that, this is Denise Dougherty, sort of, the services committee is kind of the implementation committee for, hopefully, the most evidence-based research we can get, right?

So if you think along the translational continuum, which I know NIH is doing, and many others, the research, including services research and implementation science, feeds into how and what you implement into the service system and the policy arena.

Dr. Burton-Hoyle: This is Sally Burton-Hoyle and I had a question similar to the previous speaker, in that, once we get in committees will we be able to flesh out, make more specific, regarding services? Because

the evidence-based practice piece was something I was, you know, looking to see, very straightforward to see, was that specifically mentioned?

Because so many things are based on the National Standards Project. We will get a chance to talk about that once we're in committee?

Dr. Daniels: Well, we can add those things to the list. We were trying to fit things on a slide, but evidence-based practice could certainly be involved in that whole parenthetical.

Dr. Insel: But what I'm hearing, this is Tom, is that, just by way of summary, it sounds like this first group is more services and policies, is that fair to say? With safety being incorporated in there, but maybe not -- do we need to actually specify safety or is that considered to be part of the whole issue of policy?

Ms. Abdull: This is Idil, I was

wondering if education is going to be part of the services or would it be possible to say services and education or services and safety?

And I just wonder where we fit education, because that's so important?

Ms. Lewis: In the past, it's been services.

Ms. Crandy: This is Jan Crandy. And what about medical treatment for the child? Isn't that access? That's part of services that a child should be getting. Would that be --

Dr. Insel: So access is actually the first piece under services.

Ms. Crandy: Right.

Dr. Insel: So issues of access would be services; it would also be relevant to policy.

Dr. Burton-Hoyle: Yes, this Sally again, I'm working with Detroit/Wayne County, and we've got things broken into similar kinds of committees, and access is what we're

calling that just because, simply, where do you start? That's kind of the main issue, so I think it's access as one part of it, or access to services, and then within that, what are the lifespan services that people will need and we need to enhance?

Mr. Robertson: This is Scott Robertson. A comment that I just wanted to make is that, I agree with at least making changes to the science subcommittee name because it does give the impression that it does contain all sciences. And it is, as some others have pointed out, more of a substantive science.

So by putting in biomedical, behavioral, or some kind of more specific descriptors on there, I think that that would make some other people feel comfortable rather than saying, this is all science when that's not really -- I mean, all the research there is science, but it doesn't contain all the science on autism in the plan because some of

it falls within the domain of the services subcommittee.

Dr. Daniels: Certainly. So --

Mr. O'Brien: This is John O'Brien. I just had a process question here, because I think we've got a lot of good ideas that we're talking about, but is your intent, or Susan's intent, to try to at least gather the two or four chairs and some of the committee members of both of these meet, come up with some sort of mission so we have some kind of clear lines of demarcation between the two committees?

And then go from there to be a little bit more specific about the areas of focus and then specific activities?

Dr. Insel: Right, John. The idea here today is just to establish the two groups, to establish the membership, and the leadership, and then those groups will begin to meet and actually map out what they'll be doing. Of course, because there's some urgent

needs, we want to make sure that both groups attack the questions in the strategic plan, because we need to have that done in the next three or four months.

But absolutely, I mean, the process here will be for the groups to define much of what they want to take on over the next two years and all we really need to do today is to give you the, sort of, general outline, general landscape, of, you know, what areas are going to be most relevant to each group.

You know, I hear the need to come up with names that are a little more descriptive, and if people thought that calling one of them science means the other one doesn't involve science, then I think that's a problem that we do need to make sure we address.

So I'm not sure the name has to be perfect, but it does need to be acceptable to everybody.

Dr. Daniels: So, yes, if we can get to a name then we'll have to establish it under FACA officially. So I heard biomedical and behavioral research, and I don't know if anybody else has a better suggestion for the first, what was the science, and then for the services group, it sounds like there are lots of thoughts, but does somebody have a proposal of an actual name that they think will work?

Dr. Mandell: This is David. I think that the only reason that I brought up the suggestion in the first place was to make it clear that that committee had a scientific mission as well, not to, in any way, demote the services aspect of the mission.

So what if the name were something like policy, services, and services research?

So that all were covered.

Dr. Insel: Say that again.

Dr. Mandell: So policy, services, and services research.

Dr. Cordero: This is Jose. I



think that one of the key things -- I think that what David suggests is very good. The key thing here, it seems to be the word is access, because it is about how individuals that have autism or are affected by autism have access to what area is the newest approaches for intervention or whether we're talking about housing, employment, et cetera.

And it's just, how do we ensure that we're accessing stuff, with that in the title at least it's clear that that's one of the key aspects of what this committee wishes to do.

Dr. Insel: Well, I think, you know, Jose, the way to ensure it is to be on the subcommittee.

Dr. Cordero: Okay.

Dr. Insel: Really, the title won't matter, but the people who serve are going to have to make the priorities for what gets to become the focus.

Dr. Cordero: Right.

Dr. Insel: And as we describe this, we also would have agreed that access is probably way up front. That's why it's the first thing mentioned, but it's going to be up to the subcommittee to think this through. David's proposal sounds like it's captured a lot of what the conversation is.

Ms. Dougherty: Well, this is Denise, I actually am concerned about the biomedical and behavioral title for the sciences for the reasons we've just talked about, which is services, and now we have translational science. And I would like to see translational science in there.

And I know it's hard to separate translational science from service science, but I'm really concerned about just limiting it to biomedical and behavioral. Does that include economics and policy research?

Dr. Insel: All of that, Denise, would be under the services arena.

Ms. Dougherty: Services? Okay.

Dr. Insel: Yes, but it could be a basic and translational research.

Dr. Dawson: Right. So I guess one question, would you consider, David, implementation and dissemination science part of translational research? I know there's so much discussion about what translation means, so that would be the only question.

I do like the, this is Geri, for the second group, you know, something as simple as services research and policy, you know, which is very similar to what David suggested, but that might, you know, capture that one.

What would be outside of the behavioral and biomedical research that you're thinking wouldn't be captured under that?

Dr. Insel: Who are you addressing that question to?

Dr. Dawson: The person who just spoke that was worried about that that wasn't really capturing -- I'm trying to think of the

kind of research that wouldn't be considered biomedical and behavioral. What would be missing?

Ms. Dougherty: Organizational research. Research about the underlying organization of care delivery. The kind of research that AHRQ does.

Dr. Birnbaum: Excuse me. Could I speak? This is Linda Birnbaum. I kind of think that I think what I was hearing, that Geri was saying, that the suggestion of the title of the first committee should be biomedical and translational research, and then the other one was the services and the policy, I think, really kind of incorporates everything that people have said that they want to be sure is captured under this kind of a translational term.

Ms. Crandy: This is Jan Crandy. I'm nervous that the public wants to see environmental research included and not even having that word in there at all.

Dr. Birnbaum: Well, biomedical and translation includes environmental health issues.

Ms. Crandy: Right. And I understand that, but I think that it's pretty strong that people want more money to go towards environmental research.

Dr. Daniels: So these subcommittees can come up with whole paragraphs to describe what they want to do, but probably for the title, we'd want to stick to, you know, four or five words, maybe, to try to capture what these subcommittees are so that it's simple for us to talk about them.

And then if you want to have an extensive description that the subcommittee will work on to explain all of the different things that you would like to work on, that could be a separate issue.

Ms. Abdull: Hi, this is Idil. I think, based on what everybody wants and so compassionate about, the science, if we say

biomedical and behavioral research, I think it covers, including environmental, including all sorts of science, and then for the other one, the services, I think David said it well, services, policy, and research; something to that effect.

And then within those, then we can cover more specific things based on what's in the group that you belong to, then you can come up and you can say, this is more important to me, or my constituents, or my state, how do we address this? But if we can just come up with, maybe, three words for each so then people are not confused what the titles are, that might be best.

Dr. Insel: So, Idil, just to follow up with that, so the two that I've heard as final suggestions would be something like David's comment, which was services, polices, and services research.

Dr. Daniels: That's what Geri said.

Ms. Abdull: I would say, maybe, services, policy, and research or --

Dr. Dawson: Or just services research and policy.

Dr. Insel: How about services research and policy?

Ms. Abdull: That's good. Yes.

Dr. Mandell: That sounds good.

Dr. Insel: Services research and policy?

Dr. Mandell: Yes.

Dr. Insel: And that would cover access, housing, employment, transition, all of the issues that we've been talking about. And then second one, Geri, again, you're comment was biomedical and behavioral research, is that right?

Dr. Dawson: I'm comfortable with that, or if people want to use the word translational, I'm actually comfortable with that too. My only question was whether David might argue that implementation science is

part of the translation, you know, argue about, where do you cut the line of translation?

Dr. Insel: Right. So we've been usually concluding T3 and even T4 research --

Dr. Dawson: Yes, that's my understanding too.

Dr. Insel: Very much in the services and policy arena.

Dr. Dawson: Yes. So I wonder whether we just stick to the biomedical and behavioral research.

Ms. Abdull: I think that's a good idea.

Dr. Dawson: I know it doesn't, kind of, explicitly capture that sense of environmental science that, you know, we may want to add, but it clearly is part of biomedical and behavioral research.

Dr. Birnbaum: Yes, this is Linda Birnbaum. I really do prefer, Geri, your suggestion of biomedical and translational



because the translational does cover the environmental in this way. You know, I'm not sure it has to be absolutely --

Dr. Dawson: Yes.

Dr. Birnbaum: -- clear by a title of a committee where one stops and where the other starts.

Dr. Dawson: That's fine with me too. I'm comfortable with the translational being in there. It doesn't imply that there's no translation in the other one.

Dr. Daniels: Right.

Dr. Dawson: Right.

Dr. Insel: That's right.

Dr. Batra: This is Anshu. For the sciences, I think that adding biomedical, behavioral, and cognitive research would be a good idea. And then I was wondering for the services, to add in, maybe intervention policy, and services research.

Dr. Insel: Well, we can certainly include both of those as the main descriptors.

I guess the question is whether they need to be in the title. If we're trying to keep the titles short and snappy, usually most people, at least at NIH, we would consider cognitive research in the general domain of behavioral science. So that would be part of the same --

Ms. Abdull: But could we vote, Dr. Insel? I guess I would vote on what David and Dr. Dawson, and then Linda Birnbaum suggested. I mean, because otherwise, we'll keep going on; everybody will have 20 ideas. I'm fairly sure.

Dr. Insel: You can see why we're interested in having subcommittees do the action here. It gets very complicated with this many people. But before we take this to any sort of vote I want to make sure we know what the recommendations are. So, Geri, could I get you to repeat where you left off in terms of -- and nomination for, if I heard it right, it was services research and policy, is that right?

Dr. Dawson: That was the one for the services one, yes.

Dr. Insel: Okay. So that would have research in it as well as covering all the issues around policy.

Dr. Dawson: Right.

Dr. Insel: And then we had a couple different suggestions for the science one, which were --

Dr. Dawson: For that one we could say biomedical, behavioral, and translational research.

Dr. Insel: Right. And so --

Dr. Birnbaum: This is Linda speaking, excuse me, my only concern with that, Geri, is then if we're going to breakout behavioral do we need to put in the environmental? I kind of thought the biomedical and translational would be inclusive.

Dr. Dawson: That would be absolutely fine with me too, because I've

always considered behavior as part of our biology.

Dr. Boyle: Linda, this is Coleen, we could say something like basic and translational research.

Dr. Insel: Why don't we do that.

Dr. Dawson: Yes, I like that.

Dr. Insel: So basic and translational research.

Dr. Dawson: Perfect.

Ms. Crandy: This is Jan Crandy. If we make sure that in the descriptor the environmental science is included in the descriptor, then I'm comfortable with that.

Dr. Dawson: Yes, must be.

Dr. Insel: And the other thing is the descriptor will have to identify what part of translation we're talking about since services research involves translational sciences, well, it's just at a different stage, but we can define that for ourselves.

Dr. Daniels: So the title that

you want is biomedical and behavioral, basic and translational research subcommittee?

Dr. Insel: No, no, no, just Basic and Translational Research.

Dr. Daniels: Okay. Basic and Translational Research. Okay.

Dr. Insel: So we could try to vote by phone or we could just ask if there's anyone who's opposed to those two recommendations; Services Research and Policy is number one, and then Basic and Translational Research is number two. Any strong or even modest opposition?

I assume that we're ready to move forward.

Dr. Daniels: Okay. So we have titles.

Dr. Insel: We have titles.

Dr. Daniels: Great.

Dr. Insel: So let's move on. So talk about --

Dr. Daniels: Talk about

membership.

Dr. Insel: Yes, let's talk about membership and since we now have the right committees and the question of who's going to be on which committee. And let me go through with you -- I can just read out the names of who volunteered. And we can walk down this list rather quickly.

So for the committee which is formerly known as science, but currently known as Basic and Translational Research, we have Singer, Redwood, Kau for Alan Guttmacher, Dennis Choi, Kimbark, Boyle, Dawson, Britton, Lawler for Linda Birnbaum, or Linda when she's available, Batra, Farchione, Robison, and Carey, and Koroshetz.

Mr. Robertson: I didn't send an email out, but I also intend to volunteer for -- this is the one that was formerly known as science, right?

Dr. Insel: Yes.

Mr. Robertson: Yes, I had

volunteered for that as well. I should be on that list.

Dr. Insel: Who's speaking?

Mr. Robertson: Scott Robertson.

Dr. Insel: Okay. The problem, Scott, is we're limited to 15 people.

Mr. Robertson: Okay.

Dr. Insel: And many more than 15 volunteers. Most of the people decided that they could be on either one and ended up, then, volunteering for the second committee. So let's go through that and then we can come back and see how we want to distribute and if there are still other people who want to switch or make changes.

For the Services Research and Policy subcommittee, we have Ball, Burton-Hoyle, Crandy, Wexler, Kavanagh, Dougherty, O'Brien, Carey, Mandell, Abdull, and we have additional space here because, in this case, we can have a maximum of 15 by statute and we have ten people who have volunteered.

Dr. Cordero: This is Jose Cordero, I should have also included my name in the services side.

Dr. Insel: You are on. So we have Dr. Cordero and, Scott, do you want to sign up for the Services Research and Policy one as well, or what do you think?

Mr. Robertson: Well, I would have preferred the basic science one, I mean, but I could be on the services one if there isn't an option otherwise.

Dr. Insel: Yes, I'm afraid at this point there isn't, but I can promise you that you'll have an opportunity to discuss everything that the other committee comes up with because, whatever they come up with will have to be brought to the full committee.

Mr. Robertson: Okay.

Dr. Insel: Any other volunteers or questions about the subcommittee membership? Thanks to all of you for getting engaged in this by email and helping us to get



this completed. I'm going to take the prerogative of the Chair and appoint co-chairs for each of these so we can just get this going and not have to wait for the first meeting to decide how they'll operate.

So I'm going to ask, or already have volunteers from, for the Basic and Translational Science subcommittee, Geri Dawson as the non-federal member who will co-chair, and I'll do this as the federal co-chair, and for the Services Research and Policy, we've got David Mandell, who has volunteered to be the non-federal co-chair, and at least in a tentative way, Denise Dougherty has agreed to do this until she knows more about what the time commitment is, which I'm assuming means that you'll agree to do it, but will --

Ms. Dougherty: Yes.

Dr. Insel: Because we'll try to make it as feasible for you as possible.

Ms. Dougherty: Great. Sure.

Dr. Insel: So I appreciate all the volunteers and people getting so engaged in this. It's kind of wonderful to see that everybody really wants to be at the table working on the issues that are in front of us.

We're eager to get these things off and running, and that's why, I think, now, with co-chairs and with numbers, we can get started to actually move forward with the business that we have to do.

Any questions on where we are, then, with the membership?

Dr. Birnbaum: Okay. Tom, this is Linda.

Dr. Insel: Yes.

Dr. Birnbaum: Just want to say that I should be able to be back on at about 12:15, so Cindy will take over for me now.

Dr. Insel: Okay. This is the classic tag team from --

Dr. Birnbaum: Right. Okay, guys. Talk to you later. Bye.

Dr. Insel: Bye.

Dr. Lawler: And I am on the line.

This is Cindy.

Dr. Insel: Okay. Good.

Dr. Daniels: Thank you. And this is Susan, I will be in touch with each of these subcommittees to help get things setup and make sure that you're on the right mailing list, et cetera. So you'll be hearing from me soon.

Ms. Redwood: Tom?

Dr. Insel: Yes.

Ms. Redwood: Tom, this is Lyn. I just wanted to make sure I heard you correct.

Did you say that there were still positions open for the services subcommittee as well?

Dr. Insel: Yes.

Ms. Redwood: Because I would be willing to serve on both; remember, Alison and I were the ones that basically formed the safety subcommittee and I'm just concerned that there's not any representation on that

committee with regard to the safety issues that we sent to the Secretary before. So I think it'd be important to have someone as a segue to follow up on those issues.

Dr. Insel: Thank you.

Dr. Daniels: That's fine, and that's, Alison, you would like to do that as well?

Ms. Singer: Sure, I'd be happy to.

Dr. Insel: Okay.

Dr. Daniels: So that's fine.

Dr. Cordero: Hi, this is Jose Cordero. I'm sorry. I'm going to have to sign off. I'm over in California in a meeting and I have to go to another meeting. Sorry I couldn't be back. Bye-bye.

Dr. Insel: Okay. We're going to move on, unless there are any other questions about the membership, to talk about some of the other business we need to take care of. We talked about the strategic plan update and

what the process would be for that. And let me just refresh your memory, I think, where we ended up with at the last meeting was to say that, rather than doing an entire plan between now and December, we would convene the subcommittees to look at the text in the, what do we know, what do we need sections, and provide a focused update on those parts as a, kind of, brief stand-alone document for what we will submit to Congress by December of 2012.

And again, I think the conversation, but you may remember this better than I, from the first meeting was to use the subcommittees to bring in some outside experts to help us to look at those two questions, what do we know and what do we need, and try to do that over the next couple of months, between now and, certainly, November, so that we can bring the whole package back to the full committee with drafts from the subcommittees for the full committee to then

approve to get this done by December.

Dr. Lawler: Tom, this is Cindy Lawler. Are there funds available if we wanted to have an in-person meeting and invite some outside experts or not?

Dr. Insel: Yes, they're limited funds. That actually goes back to the question that Lyn asked before about our limitations. We're trying to be able to do this more and on a broader scope. As you know, being at NIH, there are real limitations to the kinds of meetings we can hold right now and how much we can spend, and they all require many levels of approval.

But we have already started on that process, so our hope is that we will be able to have an in-person meeting for the subcommittees that would involve a, kind of, workshop. In fact, I think that might be coming up.

Dr. Daniels: Yes.

Dr. Lawler: Okay. Thanks.

Dr. Insel: I will describe that.

So the process would include -- it's a little bit easier than it has been in the past because you've got these data sources that have already been put together by OARC and we encourage for the subcommittees to use those as a kind of platform with which to begin this process; remembering that the previous strategic plan was from January of 2011.

So you've got quite a bit to work with. I happen to just, for other reasons, check this morning, and there have been over 2400 publications in PubMed with autism mentioned just in 2011 alone. So I mean, there's about 200 a month. We don't capture all of those, but we do give you a pretty good sense of, what are the main discoveries and the breakthroughs in each of these areas?

So this should help, but what we were thinking about here is that, what this update will look like is actually much more qualitative and it could be, actually,

relatively brief; sort of saying, these are the major breakthroughs since 2011 and these are the things that we were not aware of then, but that have become emerging needs, or emerging opportunities, that we want to be thinking about for the next strategic plan in 2013.

So I know for those of you who are new there's this temptation to kind of redo the whole document. We're hoping that you'll be able to sit on that impulse until next year when there's a little more time to think about what the strategic plan might look like.

The way to do this then, as we've thought about it, would be, just to get back to Cindy's comment, is to have some meetings and phone calls that could happen in September for the subcommittees to decide where they want to get the data from.

We were thinking about having workshops that would be more than just one day, but a couple of days, probably the



earliest feasible time would be late-October, early-November, to get external experts in. And then you could even imagine using those workshops, the way we have more recently at NIH, to actually draft the documents.

As we did it originally, we had two, or three, or maybe four experts for each of the major parts of the plan who advised us in the very beginning, five years ago, on putting these together. Potentially, even bringing the same people back, or a couple of additional people, to just say, all right. How would you update this now?

And draft it for us, and come to the meeting with a rough draft of what it might look like, and then use the November meeting to really hammer out the details and quickly put this together as a document that would come to the full IACC by December so that we could approve, or modify, and get this out in time by the end of the year.

So this was our concept. Let us

know what you think about a way forward. As I said, there's not a lot of time, but we think we can at least accomplish this much by December.

Dr. Daniels: Something that I should add, but it's not on the schedule, but that you should know about, is that, we're tentatively scheduling a full IACC meeting for October. And so that would be an opportunity for the subcommittees to bring a report to the full committee at that time.

And then we've already got some tentative dates, but, as I mentioned before, now we have this process where we have to seek approval for holding those meetings, and so as soon as we get firm dates that we're approved to have in-person meetings, we'll let you know.

But, tentatively, we have a two-day window in November, November 13th and 14th, that we could potentially use for a strategic planning workshop to cover both

subcommittees' work. And then, tentatively, October 30th for a full IACC meeting.

Dr. Lawler: I'm sorry. Could you repeat that? October 30th for what?

Dr. Daniels: For a full in-person IACC meeting where we could get subcommittee reports --

Dr. Lawler: Okay. Thank you.

Dr. Daniels: -- on how they've been doing through the month of September and October on their work. And then November 13th and 14th for a strategic planning workshop should this get approved.

Ms. Redwood: Tom, this is Lyn. I had a question about this process. One of the things that I think would be really helpful to have in moving forward with updating the plan is an initiative to go back and look at exactly what progress is being made in fulfilling the current objectives that we have on the plan.

I looked back over the 2011 update

and only one of the chapters on question 2 actually addressed what progress is being made. So until we can actually look back at the objectives and not just look at whether or not a project has been funded, but whether or not the objective has been answered, we really can't update the plan in terms of taking certain objectives off and inserting new ones.

So is there any way the OARC staff could help with that process?

Dr. Insel: Yes, Susan was saying to me what I was going to say anyway, we talked about this a little bit at the last meeting, and this comes under the general category of accountability.

Ms. Redwood: Right.

Dr. Insel: And it does seem to me that that could be the charge to the external experts, because they're really going to know, not only, you know, what's been funded, but they'll know what's been published and even what hasn't been published. You know, they

have to, if they're at the top of their field, be able to say, this is the state-of-the-art.

You know, we've done A and B, but we haven't done C and D, and that's what we were hoping to do. That's really why the focus shifted from doing a checklist on the 78 objectives and instead, just saying, at a high level here, what do we got? You know, what's really been done? What do we know? What are the breakthroughs? What's entirely new since these were drafted?

And what are also, I mean, I do think that what-do-we-need piece becomes even more relevant because people could say -- I'm sure one of the things we'll hear about is the need for tissue. And, you know, that's in the plan, but it can be refined and that becomes the platform for whatever we do in 2013.

But it's a long-winded answer to say that I absolutely agree. I think we should make that the core of what this exercise is between now and December.

Dr. Dawson: Tom, this is Geri. I hate to say this, but on November 13th and 14th is Autism Speaks' annual retreat of our scientific advisory committee. We'll be doing very similar things, but it's --

Dr. Insel: So are you volunteering your advisory committee as experts for this? Okay.

Dr. Dawson: We have a pretty full agenda. So I'm just worried about this. I don't think there's any way I could be there.

Dr. Insel: Yes, but a bigger problem might be that some of the external experts that we're looking for --

Dr. Dawson: Yes, there are a lot of them; Dan Geshwind and just, you know, several people that -- Craig Newschaffer, you know, so I don't know.

Dr. Insel: Okay. I'm glad we brought this up. It's a no. We're going to have to look at alternatives. Yes, we'll figure it out. Thanks for letting us know.

Anything else in terms of this process?

Ms. Singer: This is Alison. I was also hoping that part of the workshop to update the strategic plan, even for the short run, could try to start working on prioritizing the objectives. Right now, there are 75 objectives and they all appear as equally urgent. So I think it would be worth some time going through and trying to set some priorities.

Dr. Insel: Okay. So would you be comfortable making that as one of the charges to the subcommittees? Because, you know, they can ask that of the external experts as well.

Anything else?

Dr. Dawson: The only other thing, this is Geri Dawson, just to throw out there, and this may really be something we want to take on in 2013, and I'm very comfortable with that decision, but, you know, when we think about the way that the sections are currently structured, which I think is good, but they're

really structured as a set of questions.

And so then the deliverable, in a sense, is knowledge, you know, it's the answer to that question, so to speak. And sometimes I get a feeling that what's needed underneath that question is, you know, what is the goal, right? So, for example, if you said, you know, why did this happen?

You know, the goal would be to understand environmental and genetic risk factors in order to inform, you know, prevention, treatment, and diagnosis. And, you know, to me, that's something that's always been kind of lacking because then, when you think about -- it's hard to prioritize unless you really have refined, you know, what you're trying to achieve.

So that's the only thing that is, I think, missing, kind of, conceptually, from the framework that's there, and again, this may be something that we want to grapple with in 2013, but I just --



Dr. Insel: It sounds like a more structural and fundamental part of the plan that we --

Dr. Dawson: So just wait until 2013?

Dr. Insel: I would, unless others feel strongly that we need to do something before December.

Dr. Dawson: I'm comfortable with that.

Dr. Insel: Okay. Anything else about this process for the update? So this really becomes, now, the job of the subcommittees to think through, you know, who would be the experts, and what kinds of datasets will you need, and how to get this done.

Our own sense was, because when we did this initially, we had everybody meet at one place at one time and we had a really great discussion about each of these issues. We thought it would be helpful to have an in-

person workshop.

And it's always a little bit tough to do that with two or three months notice, but I think if people realize the importance of this, they'll adjust their schedules accordingly. We just have to figure out a day when there isn't a big advisory board meeting or something else like that. Okay.

Ms. Redwood: Tom, this is Lyn again. I have a quick question.

Dr. Insel: Yes.

Ms. Redwood: Who will be responsible for identifying the "experts" that we want to have participate in these workshops?

Dr. Insel: The subcommittees are going to do that.

Ms. Redwood: Okay. Great. Thank you.

Dr. Daniels: In September, as the subcommittees meet, you could identify your experts as well as if you have all these data

sources, OARC could provide you some of the data sources so that you can review them and start discussing them, you can even start fleshing out ideas for what you might want to put in the update, and then when we bring in the experts, add to that.

Dr. Insel: The other thing we could do, which might be helpful, is give you the list of who we used in 2007. I think that would be a good list to start with. You're not restricted to that, but it at least gets you started thinking about it.

Susan, I'm going to turn this over to you to talk about, then, other pieces of business that have to do with the publications.

Dr. Daniels: Thanks. All right.

So I wanted to talk with you about one of the other charges to the committee, which is to produce an annual Summary of Advances. And so the previous format and procedure that we had for the Summary of Advances, I know that there

was, possibly, a little bit of confusion at the last meeting because many of you are new and weren't with the committee as it's gone through a few of these iterations.

In the past, in 2007 and 2008, the committee decided that they wanted to vote on particular articles to include in a Summary of Advances that would inform Congress, inform federal agencies, the public, private organizations, and the way it was done was, they asked OARC to develop an integrated narrative describing, briefly, each of these advances and tying them together.

And what we found is that, in doing this, it was sometimes difficult to tie advances that might not be related to each other together, and so it was sometimes a little bit of a challenging document. And I think the committee felt, after a couple of years of doing it that way, they wanted to try something different.

So from 2009 through 2011, the

IACC voted to change the format and they decided to select the top 20 articles and have them summarized separately and so OARC did the writing once the committee voted on the top articles to include.

And in both of these documents everything is written in lay-friendly language for accessibility to the public, and that's an important part of everything that we do within the committee because the committee is supposed to be interacting with the public in a manner that everyone can participate.

And so IACC members asked for the opportunity to nominate and vote on articles twice per year, this is the most recent couple of years, selecting ten articles at mid-year and ten at the end of the year. And the purpose of this was so that there would be a selection of fairly recent articles that people could use in updating the strategic plan.

And only articles that were fully

published in print during the calendar year were eligible. So this is all, kind of, the history of this.

And so there are a few things that we need to decide, whether the committee would like to keep the current format, which is having a top 20 and having each article summarized separately, which allows for a little bit more detail, or if they would like to go back to an integrated narrative, or do something different.

And if they would prefer to select articles twice a year, which had some pros and cons because doing it twice a year it seemed like it was a little bit confusing for the committee, sometimes because they felt that they had just done this and they have to do it again and go through the whole voting process, or if they'd like to wait for the calendar year to end before they vote.

And if they would like to change the format so that any article that's been

published online, including e-pubs ahead of print, would be eligible, because many of you did nominate e-pubs, but then they weren't eligible because of the rules that the committee set in place.

So I'd like to hear some discussion on this and then we can take a vote on how you'd like to do the Summary of Advances for 2012. So any comments?

Dr. Mandell: Hello? Susan, this is David.

Dr. Daniels: Sure.

Dr. Mandell: I like the idea of including e-pubs, if the idea is to highlight the most recent advances that are available, then it would make sense to take advantage of that technology, but it would be interesting to hear from some people who've been through the process before about what they liked and didn't like about it that we could improve upon.

Dr. Daniels: Thank you.

Additional comments?

Mr. Carey: This is Matt Carey.

Dr. Daniels: Okay.

Mr. Carey: I mean, I totally agree with David and the suggestion of including e-pub. I think that's a great idea.

And as somebody who's been watching for a long time, you know, I think that this format of putting this out with the lay summaries has been, actually, very good. I like seeing that. I like seeing those things come through and, you know, getting that information out to the public.

I think that format has worked, I think, to me, has worked well, but I don't remember the earlier method as well to compare.

Dr. Daniels: Right. So they're on our Web site if you go to the left navigation, Summary of Advances tab, there's a little box that has all our old publications in it and you can go back to 2007/2008 to see



the old versions, but we've been using this format for the past few years.

Ms. Redwood: Susan, this is Lyn.

One of the people just asked about what the past committee members felt about the process and one of the things that was sort of frustrating to me is that there seems as though there was a disconnect between the nomination of these articles and actually fitting that information back into the strategic plan where it's useful with regard to our actual update to the plan.

It seemed like they were two separate processes that we went through. So if there would be a way to make this update actually feed into the update to the plan, that would be ideal.

And in going back and reading the actual language from the Combating Autism Act, I'm just wondering if what we're doing now actually meets the intent of the original language, because what it says is that we're

supposed to developed an annually updated Summary of Advances and autism spectrum disorder research related to causes, prevention, treatments, early screening, diagnosis or rule out, intervention, access to services, and supports for individuals with autism spectrum disorders.

And we're not really addressing those. We're just selecting specific articles. We're not saying, for example, there's been an increase in access to services or support, so this is an area we need to work in more. So I really think we need to look closely at, what's the actual language in the bill that we're supposed to do and whether or not we're accomplishing that with the way we've been doing it?

Dr. Burton-Hoyle: And this is Sally, and I want to support that, and it seems like that there should be an equal balance that would align with the subcommittees, with regard to research

articles.

Dr. Daniels: Well, this is done at the full committee level.

Dr. Burton-Hoyle: Oh, okay.

Dr. Daniels: It's not done on subcommittees.

Dr. Insel: So the way it's organized in the 2011 version is by questions in the strategic plan.

Dr. Burton-Hoyle: Okay.

Dr. Insel: So if it's not in the strategic plan then it's probably not going to show up as a research breakthrough or as an advance.

Dr. Burton-Hoyle: Okay.

Dr. Daniels: In terms of, Lyn, what you were talking about, we have tried to produce the Summary of Advances as a feeder document to the formation of the next strategic plan, and you all have been pretty effective in using it. In, for example, the 2011 progress update, you referred to many of

the articles that were selected in the Summary of Advances.

So there has been a role for it, but the kind of thing you're describing sounds sort of like this progress update that you have, sort of, put together to work on within your subcommittees and then the full committee, so that would meet that.

But in terms of a more qualitative assessment, that's something the committee would really need to do rather than our office.

Dr. Insel: But, Lyn, if I get your point, what you're saying is that the statute requires a report on a Summary of Advances not related to science, but related to other areas as well, is that the point?

Ms. Redwood: Yes, if you read it, Tom, there's just things in here, like, we're supposed to report what advances have been made with access to services and support for individuals with ASD. That's just one of the

several categories. And when you actually look at the Summary of Advances, it has things like, Emerging Practices in Technology, is one of the articles, but it doesn't really have any summary of how that's moved the ball forward and whether or not that's actually resulted in improved access and services.

So that was sort of my point in terms of, I see this as a way to really assess what progress we've made in the past year, and then that would feed directly into the plan, even though we'd start with these, there's no narrative in this actual update that says we've actually made progress in this area or we have not progress.

Dr. Dawson: So, Lyn, this is Geri. Would one solution to that be that we keep the process where we vote on the advances, so we identify the important advances, but then we also have a summary at the end that really addresses, you know, has in mind that paragraph and says, you know, you

can see from these advances that we've made progress in this area and this area, but, you know, there's nothing new that has happened in this other area?

Ms. Redwood: Exactly, because they ask, have we made advances related to the cause of autism.

Dr. Dawson: Okay.

Ms. Redwood: I think that's an important question to answer and I don't know that we really do that the way our things are structured now.

Dr. Dawson: Yes, so the idea in the CAA was to have an annual update where you're saying, within the past year, have we made an advance in this area?

Ms. Redwood: Right.

Dr. Dawson: Right. So I mean, that wouldn't be too hard. I guess the only caveat is that we're choosing the best ones, right? And one could imagine, you know, if you had multiple second-tier activities, but

that still made progress in that area. I mean, it almost requires a full assessment of what happens in the literature rather than just choosing.

Ms. Redwood: Right.

Dr. Dawson: You know, I think it almost fits more into what we're trying to do in the larger strategic plan where each year we say, you know, what has occurred; what's still needed, right? So we are kind of addressing that in our subcommittee work as part of our charge for updating the strategic plan.

And so perhaps we could maybe refer back to that in some way, or use those paragraphs.

Ms. Redwood: Right, to make both of those documents feel like they're congruent and they're actually beneficial for each other.

Dr. Insel: Other comments or thoughts about this?

Mr. Britton: Hello?

Dr. Insel: Yes.

Mr. Britton: Hi, this is Noah.

I'm just wondering about the twice a year versus once a year. I'm feeling like this year we'll probably only be able to do once a year, is that right; as far as the Summary of Advances? So maybe we should look at 10, 20, or something like that, by the end of this year?

Dr. Daniels: So what we would do, if you were going to do it for just once this year, we would do this in January --

Mr. Britton: Okay.

Dr. Daniels: -- and then ask to go back through all of 2012 and choose the articles. If you were to do it twice a year, in September, you would need to do a voting process, and then we'd have to do it again in January. So it depends on how much the committee wants to do the whole voting process; if you'd like to do it twice or if



you'd like to do it once.

Mr. Britton: I vote once, but I'd love to hear other thoughts.

Ms. Crandy: This is Jan Crandy. Wouldn't it be beneficial for the subcommittees to have this information for their meetings too if we did it in September?

Dr. Daniels: That was the reason that, originally, the committee had wanted to do it twice; however, you know, you will have a lot of work to do with the other items, so it depends on whether the committee would like to also be doing that at the same time.

Ms. Singer: This is Alison, and given that this year we have no choice and we have to do it once a year, maybe we can come back and revisit this issue of whether we do it once a year or twice a year after we, kind of, experience having done it once a year and twice a year.

Dr. Daniels: That's an idea. And part of the charge of the subcommittees in

doing the progress update will be looking at literature, which you can in a number of ways, so it doesn't mean that you have no access to literature just because you're not going through a voting process.

Dr. Insel: So what I'm hearing is, we're going to do once a year for now, that we'll use e-pubs, and that we'll, generally, continue with the current format, but with the consideration that Lyn brings up about, when there are advances that aren't really aligned with what's in the strategic plan, such as issues that have to do with access, or services, or something else in the realm of policy, that we should have some text in the document that addresses that as well, because it's in the CAA as a requirement.

Dr. Daniels: So if we need to add additional information in that was not a part of articles that were voted in by the committee, OARC will need input from the committee to develop that language because we

wouldn't want to take on the responsibility of making that qualitative assessment ourselves.

Dr. Insel: But it may be that it's not even in an article, but it would be something that could be captured. You know, if there's a new policy in a given year, or a new change in legislation, or something like that, where you simply have a paragraph.

Dr. Daniels: That's true.

Dr. Insel: And it could be that the subcommittees could be helpful there.

Dr. Daniels: Sure. Yes, the subcommittees, maybe, could help us in listing some other types of resources that indicate progress.

Dr. Insel: Okay. Can we go on, unless there are any other comments about this?

Dr. Daniels: Can we take a quick vote? Maybe we can just see if there are -- anybody opposed?

Dr. Insel: Yes, any concerns

about that process going forward? Anyone opposed? Hearing none, we're going to move on to the next piece of business, which has to do with the portfolio analysis. And, Susan, you can take us through this as well?

Dr. Daniels: Okay.

Dr. Wexler: Hey, this is Larry Wexler from OSERS. I just wanted to let you know I am on the call. I came on a little while ago. Thank you.

Dr. Insel: Okay.

Dr. Daniels: All right.

Mr. O'Brien: And, Tom, this is John O'Brien. I apologize. I have to drop off for a presentation. So I just wanted to let you know that.

Dr. Insel: Thanks for letting us know, John.

Dr. Daniels: All right. So the portfolio analysis. We did talk about this at the last meeting. Just wanted to briefly recap what this document is. It's a

quantitative analysis of the ASD research portfolio across both federal agencies, which is required under the Combating Autism Act, and private organizations, which is not a requirement, but it's something that has become a tradition of this committee, largely because the community is so deeply involved in autism research.

And the committee felt that it was prudent to be able to assess what was going on in those organizations as well so that you have a full picture of the research landscape.

This document, that is prepared by OARC on behalf of the committee, assists the committee in fulfilling its requirement under the CAA to monitor federal activities.

And it informs the IACC and stakeholders about the whole landscape, highlighting gaps and opportunities that can guide future activities across federal and private organizations, and can serve as a foundation for other analyses, especially

because, recently, we have released all the data in a publicly-accessible format in the portfolio analysis web tool, so now everyone in the public can get this data and use it to perform additional analyses that can be used to inform the community.

So the purpose of bringing this up is I'd like to get approval from the committee to begin the data collection for the 2011 portfolio analysis. And one issue that we wanted to bring to your attention was that, we have, currently, eight private funders who are included, and under the Paperwork Reduction Act, we are only allowed to include nine, unless we get OMB clearance to be able to collect data from more.

And so since we only have eight, we have room to collect data from one more funder until OMB clearance has been obtained.

And so I wanted to get your input about other funders that we might want to approach, see if they'd like to participate.

I'd like to bring your attention to the fact that, within the last couple of weeks, two Fragile X organizations have approached us. FRAXA and the National Fragile X Foundation have expressed great enthusiasm in trying to join this effort and offering their data.

We would only be able to take data from one, but I wanted you to know that they voluntarily came to us asking if they could join. Last year, one IACC member mentioned the Hussman Foundation, and we could, potentially, ask them, and there are other family foundations that may be interested.

So I wanted to see if anyone on the committee has suggestions for additional private or federal funders that OARC should be checking to see if we might be able to fill in this one funder, and OARC will be trying to obtain OMB clearance, but it's a several-month process, so I don't know exactly when that will be completed.

So any suggestions from the committee?

Dr. Dawson: Susan, this is Geri.

This is not quite the question you're asking, but I did want to bring up, you know, the issue about services versus research. And this is the report where we're finding out about funding in different organizations, is that correct?

Dr. Daniels: Yes.

Dr. Dawson: So one of the things that I was thinking about was that, if the federal government is going to be including services, such as the LEND Program, in their estimates, then the other organizations should do the same. So, you know, I've never really included where there's a whole section on professional training, and services, and toolkits, and so forth, that Autism Speaks funds because I specifically was only, you know, providing the funding on investigator-initiated research grants.



We didn't even include, you know, some of the infrastructure things that have to do with the, you know, databases we oversee and so forth. So I'm just a little bit worried about this apples-and-oranges issue, and mainly because there are a lot of analyses that say, you know, this is how much the government's doing, and this is how much the private groups are doing, and this is how this has increased and that has increased.

So I just think we have to make a decision to decide on what's going to be included in the report, and then I'm happy to provide any, you know, information that's needed.

Dr. Daniels: Well, I can address that concern about the services, additional grants and contracts that were included in the last report. The purpose was to be inclusive of any types of projects that we felt were responsive to the strategic plan that would be of assistance to the committee to know about.

Our staff did go back and check all of those projects that were in question and they all contained various aspects of evaluation of new, modeling, innovative practices, and that was responsive to the strategic plan.

So that differentiates it from an ordinary services provision of standard methods of approaching practitioner training, et cetera, and it's sort of analogous to the research workforce section in Chapter 7 that's really focused on biomedical research.

So we will have more clarification on the Web site about the details of those projects in the coming weeks, but they have been checked and they were responsive to the plan, so they are different from just ordinary services provision-type activities that were not included.

Dr. Dawson: Okay. So I guess then the question would be, if we're involved in service activities, for example, at Autism

Speaks, where it does involve an evaluation component, should we also be including those when you approach us?

Dr. Daniels: Yes. And Autism Speaks did have some projects in 5.L.C. that did include an evaluation component, so some of them were there, but I don't know if --

Dr. Dawson: Yes, I don't think we included -- you know, there's a pretty substantial component of what we fund that I think probably falls in a similar category that wasn't included.

Dr. Daniels: The thing that our office can do is provide even more detailed guidance.

Dr. Dawson: Okay. Yes, that's fair. I think as long as we're doing apples to apples then --

Dr. Daniels: Right.

Dr. Dawson: -- I think it's fine.

You know, it does get into a blurry line about what's research, but I think that's okay

probably.

Dr. Daniels: Right. And services research is a little bit broader --

Dr. Dawson: Yes.

Dr. Daniels: -- than medical research and we want to be inclusive and not ignore the important advances that are being made in that area.

Dr. Dawson: Yes, I agree. Okay.

Thanks.

Dr. Daniels: So based on that, does anyone have any suggestions on funders that OARC can approach, and I'm not guaranteeing that, of course, we can't include all of them unless we have OMB clearance, but we would approach them and see if they're even interested.

Dr. Insel: Susan, can I break in here for a second?

Dr. Daniels: Sure.

Dr. Insel: I went back to this document that you got at the meeting, Autism

Spectrum Disorder Research Publications Analysis, this is the one that looks at everything that was published in 2010 worldwide. And there's this really interesting table, which is on Page 30, I don't expect you to have it in front of you, but I'll describe it very quickly.

It's the funders as they were acknowledged in publications and it's a list of 27 such funders stacked up by the number of times they were acknowledged in publications in 2010. And what's surprising to me about this is that, in the top five, three of them are outside the United States.

So the Medical Research Council, the European Union, and Wellcome Trust. Wellcome Trust is a very large private funder of biomedical research in the U.K. So I am assuming that the committee wants to focus on the U.S. support and not on others, but just to remind us that the U.S. support is really a fraction of what's being done today in autism.

And in fact, in the biomedical realm, if you look at the delta, that the areas that are increasing the most quickly are outside the United States, not within. The second comment about this is that, some of the ones that ranked fairly high here were actually groups like FRAXA, the groups that are focused on either Fragile X or related disorders.

So Nancy Lurie Marks Family Foundation was in this. And then there are some groups, like the Howard Hughes Medical Institute, which, while it's not high in terms of the number of publications, is a very large funder and provides a huge amount, it's the largest private funder of biomedical research in the United States, it's a little bit like the Wellcome Trust in the U.K., but they have gotten into autism as well.

And they have not been part of our analysis in previous years. So I thought it was worth, as a committee, just stepping back

from this and reminding ourselves that there are lots of players in this space, many of them are outside the United States, many of them are not being captured by what we're doing.

But if we can add one more, whether that would be a group like Howard Hughes or the group that used to be called NARSAD that's now the Brain and Behavior Research Foundation, they're way up there actually.

They're one of the highest. They're in the top ten of funders. And if you just look in the United States, they're in the top five in terms of publications with acknowledgments.

So if those data are helpful, that may be one way to guide our thinking about how to get additional information about what's being funded.

Mr. Carey: Tom?

Dr. Insel: Yes.

Mr. Carey: This is Matt Carey. I don't have that in front of me, but I mean, the two names that came up when you first mentioned this were Marks Foundation, that I think you just mentioned, the one in Boston, I think you just mentioned, and Lurie Marks, but I don't know where they lie on that list. I had forgotten. It's just been so long.

Dr. Insel: Yes.

Dr. Daniels: So, like, I can answer. Last year, the committee asked us to approach Nancy Lurie Marks and they elected, at the time, not to participate.

Mr. Carey: Okay.

Dr. Daniels: But these others have not been approached, and FRAXA and National Fragile X have approached us.

Dr. Insel: What about Brain and Behavior Research Foundation?

Dr. Daniels: We have never asked them.

Dr. Insel: Because, just in terms



of the number of publications, they're way up there, well, that and National Science Foundation. Are we getting NSF money?

Dr. Daniels: NSF is included.

Dr. Insel: Okay.

Dr. Daniels: It was included this year and they had about a \$10 million portfolio of new research that we included.

Dr. Insel: Okay.

Ms. Singer: So this is Alison and I think it makes sense to broaden the reach because the goal of this exercise is to get a realistic picture of where the funding is going, but I want to point out that there is a big difference between, in the reporting requirements, of a public charity, like Autism Speaks, or Autism Science Foundation, or FRAXA, and a family foundation, like Nancy Lurie Marks, or some of the other family and private foundations.

And I think it's very important that if we're going to include family

foundations and approach them about participating, that they be willing to open up their books the way we do so that we are really getting an apples-to-apples comparison.

There can't be any anonymous or, you know, we donated this much to genetics, but we're not going to say where or to whom. They have to be willing to provide the same level of transparency in this exercise that the other participants do.

Dr. Insel: And that was the issue last year, Alison, that we ran into with Nancy Lurie Marks.

Dr. Daniels: So based on that, are there -- I don't know if the committee would like to prioritize a few of these for us to ask. I heard Brain and Behavior Research, any support for any others that we should ask?

Ms. Abdull: Hi, Susan. I was wondering, maybe Howard Hughes Medical Center.

Dr. Insel: Right. Okay.

Dr. Mandell: Could I ask about

the training and, Susan, I may have missed something when you described how this training and professional development funding that you'd be counting differed from other sources, but it seems like something that would be much more difficult to get an accurate count of than research funding.

Dr. Daniels: So part of the definition that we were talking about was described in the strategic plan because there is an evaluation component that these are pilots or trials of, kind of, new, innovative approaches. Broadly, they could be defined as research and that's how our office approached those types of things.

So in federal funding, we were able to identify those. Although, if they are private funders who are doing that, it's possible that, if there wasn't enough detail for them to understand that they needed to include that, the way we could address that next year is to just provide more detail about

what we're looking for to make sure that everybody knows that they should let us know about this project so the committee can be aware of it.

Dr. Insel: So we can spell that out much more clearly on the site, so there'll be less ambiguity next year.

Dr. Mandell: And did you include the Institute of Education Sciences in that?

Dr. Daniels: Yes, it was in there.

Dr. Mandell: Okay.

Dr. Insel: So we had their numbers from last year.

Dr. Daniels: Yes.

Dr. Mandell: Okay. And that included their professional development activities as well as their research activities.

Dr. Daniels: Yes, it did.

Dr. Mandell: Okay.

Dr. Batra: Tom?

Dr. Insel: Yes.

Dr. Batra: This is Anshu. Are we limited by a mandate to just look at the U.S. agencies? I mean, it seems to me, one of the big messages that resonated from our meeting was the sense of urgency and frustration. And I think that, as you mentioned, one of the greatest, sort of, increase in interest is of this environmental aspect.

I mean, I get that question repeatedly from patients. And I think that if we have, you know, three out of the top five, as far as foundations, that are outside the country --

Dr. Insel: Yes, that's a good question. And I was actually stunned until this report came out. Just at our last meeting, I had no idea. This is not what, I think, any of us would have assumed. It's interesting. If you haven't looked at it, take a look at this paper because it's a real wake-up call for where a lot of the --

Dr. Batra: I'm looking at it and I'm stunned. And, you know, I would think that we would be, you know, chasing -- you know, basically, casting wide.

Dr. Insel: Yes. So, Susan, what do you --

Dr. Daniels: Yes. So I can address that. For the normal IACC portfolio analysis, to meet the mandate of the CAA, we should be sticking to U.S. funders, but OARC actually, even internally, has expressed interest in the possibility of doing an international analysis if the committee felt that would be useful.

And so it's a project that, if the committee is interested in having us do, we could try to add it to our calendar to do as soon as we get some of these other CAA-mandated activities under way, and assuming that we have the appropriate budget and staffing to be able to accomplish such a task.

But we actually are prepared and

the work that we did on the publications analysis has given us some new tools that we have now developed that we can use to address this issue. And the other thing is that, with the OMB clearance, we were planning to request OMB clearance to get international funding information.

So if the committee feels this is important, this would be important to let us know now so that we can plan.

Dr. Insel: The other part of this that'll be really interesting is, as we do the Summary of Advances that we just talked about, that's not being driven by just U.S. funding or U.S. scientists.

Dr. Batra: Right. Exactly.

Dr. Insel: So it'll be really interesting to see, out of the top 20, how many are outside the United States and I think that'll be the other way of thinking about this, aside from just where the funding is.

If most of the breakthroughs are

taking place outside the United States, it raises some really important questions for us and might be one of the ways in which we can also provide some feedback to the Secretary that she ought to know that, in terms of the global picture, we're actually maybe not as competitive as a lot of people assume.

Dr. Wexler: So this is Larry Wexler. I actually represent the United States on the International Bureau of Education, which is a UNESCO Bureau, and I would concur with what you all are saying. There really is a whole world out there of activities around disability and funding of disability research and practices that is very ongoing and very extensive.

And certainly, I would support expanding, including in some way, shape, or form, what's going on around the world.

Ms. Abdull: Hi. This is Idil. I'm, you know, actually not even surprised because autism is not just a U.S. problem,



even though it's growing here, it's growing internationally even as much.

And so I would like to include and look at how other countries and other foundations outside of the U.S., the kind of research they're doing, because autism is so much, not just genetics, but it's also about environment, it's also about behavior, and then different countries, different climates, it's important to look at how other countries, and other environments, other factors, are contributing.

So it would be a good idea to look at this, not just from the U.S. lenses, but also from a global point of view.

Dr. Daniels: Great. So it sounds like there's pretty strong support for having OARC do an international portfolio analysis project, so that's something we could look at the feasibility for.

Dr. Insel: So let me just remind you that a lot of the information that's in

this report, that you got at the last meeting, captures, at least, where the action is. What we're talking about for the portfolio analysis is the specific funders and funding.

So we can go down this path. It's not clear that a group in Germany, or Japan, or anywhere else will necessarily give us the information, just as some of the foundations in the United States have not been willing to share the information. We're asking for very granular information about everything that they're funding, and who they're funding, and how they're funding.

So it may be more of an aspirational goal, but take a look at the publication that we did put together that captures 2010, and that will, I think, be interesting for you to see the global picture as it is now.

And, obviously, this is focused most on biomedical science because most of these funders, like Wellcome Trust and the

Canadian Institutes for Health Research, these groups are really focused on most basic science, but it's a pretty good indication of where the research is going.

Mr. Robertson: Tom, could I ask a question? This is Scott Robertson. What I wondered is if there's any part in this, I mean, I don't know whether this fits in or not, where there could be a recommendation to the Secretary on having some kind of loose, informal, kind of, international body, or community practice, online or otherwise, that could be a part of, kind of, forming these, kind of, connections of different bodies that are funding research and what it's looking like in terms of publications to have more of an open sharing among the international community?

Dr. Insel: Yes. It's a really interesting idea. There's a lot of interest in data sharing, especially coming out of the European Union, and so in other areas we're

seeing lots of progress in that arena. Let's do this. Why don't we actually get more information, we already have what you saw at the last meeting, and we'll continue to track that.

And then maybe we can circle back to this issue and dig deeper into what might be worth pursuing. I do think that several people have said, you know, we are a part of the picture and for us to be focused on just the U.S. is what our mandate is about in the Combating Autism Act, but increasingly, as the years go by, it's clear that that's not the whole story.

Ms. Abdull: Do you think the United Nations, if we connected with it, because I know that autism is important to them, I wonder if --

Dr. Insel: Yes, that's a good thought. There was somebody at the IACC who's been very involved with the U.N. who asked the same question.

Dr. Dawson: This is Geri, and there is, actually, quite a bit going on at the U.N. right now and we're pretty deeply involved with that, but I just don't know what I'm able to disclose. But there are resolutions underway, and resolutions already been made, and active subgroups that we've been involved in that are gearing up to have the United Nations take a more, kind of, leadership role in the autism arena.

So what I could do is go and check with the folks that are working on this and just see what's public knowledge at this point. But just to let you know, there's a tremendous lot going on, and many nations involved, and I think it's going to be a pretty exciting year at the U.N.

Dr. Insel: So, Geri, what about if we put some time aside at the next full committee meeting to hear about a more global perspective, and it could include what went into this report, which is pretty cool, and it

has some interesting timelines that show, you know, who's doing what, but then, some of the plans, both at the U.N., and maybe some best practices that are emerging from some unlikely places.

So we can talk more about it, we've got a few months before that meeting, but I think it would be of real interest to the whole committee.

Dr. Dawson: Great. Yes.

Dr. Daniels: And we can bring this topic up again. In the meantime, our office can look into possibilities for what we would need to do to be able to do such an analysis, although, I don't think it would be something we would start until calendar '13.

So in terms of funders, Brain and Behavior Research, HHMI, did you want to include FRAXA or National Fragile X on the list of people to ask? Did you have any other suggestions?

Dr. Insel: We can only include

one?

Dr. Daniels: We can only include one, so if I have this prioritized list we can go down the list and include the first one of them that is willing to supply data.

Dr. Insel: Yes, from the table, Brain and Behavior Research Foundation has double the number of citations as FRAXA. I don't know what that means in terms of money, but that might be a good guide. Why don't we start there and see what we find out.

Dr. Daniels: Okay. So we will look to try to include one more and then see how fast the OMB process goes to open up the possibility of including others.

Dr. Insel: Why don't we move on. We've got lots more to do.

Dr. Daniels: All right. And then the last slide, I believe, for today is the workshop slide. I wanted to talk about how IACC workshops work. The IACC, under the Combating Autism Act, is permitted to convene

workshops on areas of interest that are pertinent to the community.

And recent IACC workshops that we've had included a 2009 IACC scientific workshop which sounds like it's quite similar to what we're thinking about for November, where we'll bring in experts that can help advise on the strategic plans, or the strategic plan progress update.

In 2010 and 2011, the services subcommittee proposed workshops to the full committee and were approved, and so they had two services workshops; Enhancing Supports for People with Autism and Their Families: Community Integration and the Changing Delivery System, and the workshop: Building a Seamless System of Quality Services and Support Across the Lifespan.

And we had a number of experts from federal, state, local, private organizations who were working on various aspects of services. The subcommittees and



working groups within subcommittees are generally responsible for proposing and planning workshops, and any proposals have to come to the full committee for approval.

Based on our current budgetary constraints, the recommendation would be that, perhaps one additional workshop could be planned in 2013 and if it turned out that there were funds available to have a second workshop, we could do that.

The subcommittees can be working on generating topics, although I think it sounds like the fall will be fairly busy, but if the subcommittees have time to throw around some ideas about what kinds of workshops they might address within, and hone in on a specific topic that they might want to include for 2013, we can look at the possibility of holding a workshop, but we will need many months of lead time to be able to plan such a thing.

So I wanted to let the committee

know that that was something that's, you know, within the possibilities for these subcommittees to do.

Dr. Insel: Good. Any questions or comments about this? Okay. That, I think, concludes the business, unless there's any other business from the operations of the committee that took place.

Ms. Redwood: Hey, Tom?

Dr. Insel: Yes.

Ms. Redwood: I'm sorry. I was on mute. I was looking through the actual update portfolio analysis and under question 4, "Which Treatments and Interventions Will Help?" there's actually an objective to convene a workshop to advance the understanding of clinical subtypes and treatment personalization, and that had a budget of \$50,000, and we have no research going towards that.

So I was wondering whether or not we, as a committee, or if one of the NIH

institutes, would take on actually fulfilling that particular objective to convene a workshop and that would give us more workshop information to be used in updating the strategic plan since we have limited funding.

Dr. Insel: Right. Yes. We did have a workshop on biomarkers to try to identify subgroups and we can report out about that. And there should be a published document from that, but I would say that, you know, this would be the task of the subcommittees to decide what they want to do as the next focus.

And, you know, we could go back to that issue because it's still a very hot issue and a difficult one, or the subcommittee may want to think about what's the highest priority.

Ms. Redwood: Yes, and the one on biomarkers, that one was one of the questions in three was to convene a workshop that looks at the usefulness of --

Dr. Insel: Right.

Ms. Redwood: So we did do that one, but I don't think we've done the other one, which was looking at clinical subtypes, so that's why I was bringing it up.

Dr. Insel: Okay.

Dr. Daniels: And the ethical legal and social implications workshop that was in, I believe, question 1, has already been done as well by NIH.

Ms. Redwood: Right.

Dr. Daniels: So, yes, so that's a possibility. So the subcommittees will need to prioritize topics and then if each subcommittee wants to come up with a proposal for the full committee to consider, and consider that at a future full committee meeting.

Dr. Insel: Anything else? So that takes us to a discussion that we did not get to have at the previous meeting. We heard about 30 minutes or so of public comments, and

you received lots of written comments, both from those who spoke publicly and those who didn't.

We have always set aside some time in the meeting for a discussion, and reaction, and further thoughts about that. We ran out of time to be able to do that at the previous meeting, so I wanted to make sure there was a chance to do that today, and this is that moment.

We're going to open this up for anybody to discuss anything that they want to follow up on from what we heard at the first meeting.

Dr. Dawson: So I'm sorry to jump in here so quickly, this is Geri, but I have to leave in five minutes and so I was hoping to at least make one comment about this, because I do think the public comments are so important. And, you know, what really struck me about them was the interest and understanding the causes of autism and

environmental risk factors. That just came through loud and clear.

And obviously, people are interested in different types of environmental risk factors, but it does seem to be an issue that's on our community's mind. You know, why are we seeing this rapid increase in prevalence? You know, what environmental risk factors could be contributing to this? And how does this inform, you know, prevention efforts?

And so I think that just was a theme that seemed to come up. And then the other one is that, I do feel like there's a bit of dissatisfaction in terms of doing the full follow through on our emphasis on wandering and I know that we really made some great strides there in terms of funding a study that was through IAN and finding out more about the prevalence and some of the context in which risks for wandering is increased.

And we also were able to, you know, get a medical code for wandering. But there still is this sense that, you know, we need to do more in that area and that there hasn't been a full response by the IACC back around that. And so I don't know exactly what that should involve, but I think it is something that I'm hearing from the community. So I just wanted to mention those two things. Thanks.

Dr. Insel: Geri, I'm sorry, could you just clarify when you say a full response by the IACC.

Dr. Dawson: Well, I think that the people are, you know, perhaps wanting more than just putting a medical code in place and I don't know whether it's more of an Internet, you know, people have talked about having an alert system or having better tracking of how frequently this occurs.

I just feel like it hasn't quite -  
- we haven't come full circle in saying, okay,

we feel like we really addressed what was a very specific targeted issue that the IACC took on. And, you know, even the response from the Secretary, you know, has not been, perhaps, as robust as people might have wished for.

And so the sense, when I talk to people, is, they're still kind of waiting to hear. Maybe it's a report, right, that we need to go back to the community and say, this is what we've done, and this is what we found in the IAN report, and this is what we think, you know, needs to be done going forward.

Ms. Singer: So this is Alison and I think that in the document that the safety subcommittee wrote in the last IACC, we actually mapped out a plan for what needs to be done. The first piece of the plan is to gather the data, which was done, and the second piece was to work on getting the ICD-9 code, which is now done, and the next item, while I agree that it's important to report



back on what we've done, I think we also need to move forward.

And the third item was to really convene a delegation of IACC members to go and meet with the Department of Justice and to include HHS in that meeting at the Department of Justice and really push for this autism-specific alert.

And we had started down that path, Lyn and I particularly, with setting up meetings at the Department of Justice, and we spoke with Susan about the FACA rules that were involved there, and then when the IACC sunsetted, we were not able to continue with that business.

I strongly feel that we need to move forward with that and approach this woman at the Department of Justice who had indicated interest in dealing with that and try to move that forward.

And I'm happy to take that on, and I'm also going to volunteer Lyn here, to

continue to work with me as co-chair, or, you know, however, now it's David's committee, but I think we really need to continue to push forward on that because you literally cannot read the Internet, or watch T.V., or look at a newspaper any day without seeing another tragic incident of wandering.

So we absolutely need to continue to move forward on that.

Ms. Abdull: Hi. This is Idil. I was wondering if I can just comment a little bit about that, so, Alison, even if you guys meet the Department of Justice and it's just people come from there, doesn't that still need -- how do we get that service of children wandering and my son is one of them? He could care less. He has no fear of safety.

How do we make sure that it trickles down to the families and to the children? So, for example, in this state, there are only a few counties that would pay for the alert system, or they call it Life

Project.

So as a family, you want to always know which pays, should you move to that county? I just wonder if it's something that should be on the child IEP. So the education department needs to step up a little bit more and if the kid is a wanderer, if the kid just likes to leave and not have any fear of safety, then we need to put that in the IEP and the education system needs to pay for it.

And then if the child has insurance, or medical assistance, Medicaid, then maybe there's a coordination, but I really think just talking about it is, as a mom, doesn't really help us. We need to figure out who should be responsible, how do we make sure that we add that as a part of the autism guide and how do we make sure that it's part of the IEP, or if the child's getting private AABA, it's part of their treatment plan?

Ms. Singer: This is Alison, I

absolutely agree, and in the document that we drafted, the most important step was prevention. You know, all of these systems, to find them afterwards, are secondary to trying to prevent wandering. But really, as you described, the key to prevention is awareness at the very local level; all of those wandering incidents occur at the local level.

But the key is to create awareness at the national level so that it then trickles down to an understanding that these policies and procedures need to be implemented at the local level.

So, you know, we certainly want to take the task of trying to do this from the community grassroots-based bottom-up, but we also need to have a top-down approach where, I think if we were able to have the Justice Department endorse an autism-specific wandering alert, that would really fuel our grassroots efforts to implement prevention

procedures locally, so I think both have to happen is what I'm saying.

Ms. Abdull: So is it possible then maybe to, Thomas Perez, the guy that we met at the White House last year, Susan, contact him or somebody in the Department of Justice and just say, you know, this is what we're thinking? And then I also would like to ask or add the Department of Education along with HHS.

Is it possible to say, we need this to have a national awareness? It should be part of, when autism is described, wandering and not fear of safety should be part of that, so even those that are diagnosing the children can ask you, because right now they don't. That's not really part of it. You have to, as a mom or as a dad, think of it and tell them.

It's not some of the things they ask you, you know, to think, like, does the child talk, does he pull, does he look at you?

Does he wander? I've never had anybody ask me until my kid started wandering and leaving.

So I just wonder if, Dr. Daniels, if you think we can do it from here?

Dr. Daniels: So this sounds like you're forming a pretty good working group under the new Services Research and Policy committee, so Geri, Alison, and Idil, and others that are on that subcommittee, can work together as a working group to organize activities.

The DOJ meetings, as Alison said, didn't occur because of the sunset of the Combating Autism Act, but now that we are reconvened, that can be discussed, so that can be a top agenda item for a September, likely, a phone call, but possibly a meeting, of the services and save it for services research subcommittee.

Ms. Singer: So can I just respond to one thing that Idil said? We did recognize, when we did that plan, that it's

important for pediatricians, and family practitioners, nurse practitioners, and school nurses, to be talking to families about wandering.

And so now that we collected the data, we took that data to the American Academy of Pediatrics and they are including a question about wandering in the new toolkit that they're going to be releasing about autism.

So, you know, slowly these things are happening. They all start with actually collecting the data. And we will get another opportunity to really push on the wandering issue when the study is published in Pediatrics, and that is scheduled to happen, I don't have the exact date in front of me, I think it's in the second half of October, the wandering study will be published in Pediatrics.

So we're going to work on really pushing that in the media and using that as an

opportunity to create additional awareness about the risk of wandering and the need put in preventative measures.

Dr. Batra: Alison, this is Anshu, and I've been listening to everyone's comment, and again, as a parent, as a pediatrician, this is a very important issue. Safety, I mean, safety for any child, and, you know, having, you know, a son who's wandered myself, you know, this again, rings very close to me.

But the way I see this, I see, sort of, two different issues. One is, a local, sort of, infrastructure that we can access when, God forbid, a child has wandered, okay? And here in my small corner of the world, we end up really having resources in place, really, through the school districts and the regional centers, and if it's deemed that the child, you know, has a safety issue, then we provide more integrated one-on-one, sort of, supervision.

Then I see this national issue of,



okay, when, God forbid, a child has wandered, how do we cast out and do the best we can to find that child safe in the shortest manner? And that's where, you know, I think something like, you know, an Amber Alert, you know, maybe a Blue Alert, be in place at some point, which, again, I see as, you know, you have to jump through a bunch of hoops, and, you know, legalese, et cetera, you know, that's actually a longer, sort of, process, but I do think it needs to be, sort of, looked at and possibly, you know, at some point, addressed.

But again, I see this, again, as a very, you know, viable, as a very, you know, important issue that has to be, sort of, looked at and addressed at, sort of, different levels.

Dr. Burton-Hoyle: This is Sally, and I agree, and it needs to be community-based and comprehensive, and it sounds like, under the safety rubric, that a public campaign needs to be developed that, kind of,

hits all the different things you all have been saying.

Dr. Batra: Yes, and I have to say, as a pediatrician, listen, we have, you know, 203 mandates, little checklists, that we have to go through at every well child visit, whether it's, you know, the two month well child visit, you know, is the baby eating, gaining weight, and, you know, sleeping okay versus the, you know, five-year-old, you know, or versus the teenager?

And so, I think it's important for the awareness. I think, because, I mean, that's what we would expect for any child. But, you know, I think we should really focus this because, you know, the wanderers are going to be, you know, our children with special needs and I think that what we have in place, you know, locally, and, you know, community-based is really, you know, through our schools and through our, you know, local government, sort of, agencies.

And then, of course, nationally, we have to have some awareness so that, you know --

Dr. Insel: What I'm hearing is a lot of interest in this issue brought to us, again, through the public comment and it sounds like a topic that the new policy and services research subcommittee can get us back on track with. There was real progress in the previous committee.

And as Alison mentioned, we were still in the middle of some of the action items when the committee sunsetted, so it's a chance to get back on track.

Dr. Boyle: Tom, this is Coleen, I'm wondering if, given there was considerable progress and there are a couple of papers that are coming out. I'm wondering if this might be a topic to bring to the full committee when we next meet to actually review the progress, you know, review what the issues were that Alison outlined in terms of next steps, and

how the various agencies can, perhaps, support some of that, because I felt like a lot of work did go into planning for that.

Dr. Insel: Are you volunteering Alison to do that?

Dr. Boyle: I'd be happy to help Alison.

Dr. Insel: Alison, are you still there?

Dr. Boyle: She may have left us.

Dr. Mandell: Alison, I think she needed to go pick up one of her daughters.

Ms. Singer: No, I'm here. I was on mute. Yes, I mean, I think the timing is good. If the meeting is going to be October 30th, then the Pediatrics paper will have just come out, so maybe Paul Law can also present, but, yes, I'm happy to work with Lyn to present the work that the subcommittee did.

Dr. Insel: Great. Well, we'll put that on the agenda. Anything else on this? If not, let's move on. Other comments

that we heard that people want to reflect about or follow up on?

Ms. Redwood: Tom, this is Lyn. There were several. I went back last night and read over all of the written public comments, and the oral public comments, and, you know, trying not to elaborate on each one, but sort of summarizing them, what I felt was a frustration from several of the presenters that we're not following up on critical findings.

For example, Pam Rockwell, who was the first presenter, that talked about the maternal antibody work of Judy Van de Water and the people out at UC Davis, and how it's very compelling, and there's a lot of possible triggers that could be causing that.

She mentioned administration of immunoglobulins to pregnant women, which I think is very important that we look into those things. The other comments that we heard from Mary Holland with regard to their

investigation into the cases that have been settled in the Vaccine Injury Compensation Program, and they were only able to access something like a 1000 cases and they tried to follow-up with the families.

And in 83 of those cases, the child was also documented to have autism. And they had been compensated in the program, often times they were compensated for things like seizures, or encephalopathy, but the child also had developed autism.

And I think it's important that we try to follow-up on that and figure out why some children are having these abnormal responses. I know I hear it over, and over, and over again from parents, and it's just something that we need to take seriously and follow-up on.

Katie Weisman's comments about mercury. We have research that documented abnormal porphyrin levels in children with ASD, and that research has come from three

separate continents, and those are known to be markers for heavy metal toxicity. We're really not following up on that the way that we should.

So one of the things that -- and then also, Dawn Loughborough, she was someone who suggested that we develop some type of environmental task force. As Geri said previously, environmental research has really sort of gotten the short straw in terms of funding and we need to correct that.

And I think developing some type of task force that could review some of these findings and help us set priorities in terms of areas that we need to understand better, that can also lead toward effective treatments. It's critical and the type of urgent thing that we need to do right now.

In looking over question 7 of the strategic plan, one of the items, one of the objectives, was to create funding mechanisms that encourage rapid replication of studies of

novel or critical findings by 2011. We're in 2012 now and that's marked as a red flag in terms of not being funded.

So I would really like to see some of the institutes who sit on the IACC to come up with mechanisms to put out RFAs, to follow-up on these, to create special emphasis panels, to review these types of proposals rapidly, to go out and actually seek investigators to fill in the gaps so we can move this forward.

We also have reports from families about using nonsteroidal anti-inflammatory drugs to address the findings of years ago that there's a constant inflammatory process going on in the brains of not only children, but also adults with autism, and there's been no follow-up on that in terms of looking at what might be causing that inflammatory process or what we can do to treat it, and that's critical.

So I just want to ask that we



please listen to these families and we step up the pace of trying to really dig into these novel findings that are pieces of the puzzle.

Dr. Burton-Hoyle: This is Sally and I have a question for all you esteemed scientists. Are we considering the National Standards Project and the way and the manner in which the person was diagnosed? For instance, was everybody that's in these various kinds of studies, was the ADOS used or what was the manner of that, and/or does that matter?

Dr. Insel: If no one's going to respond, I think it's incredibly important to have standardized approaches to diagnosis. One of the areas that we're seeing in a lot of other parts of medicine is the creation of common data elements, and that may be, getting back to the strategic plan, one of the places we decide to push for the autism community as well.

There's some of this going through

NDAR, but it's not actually being done quite the same way, for instance, that we're seeing it in the ALS community and some of the communities that Walter's involved with, where they have developed, now, one set of common data elements for virtually all researchers, at least on the clinical side, so that's an opportunity here that needs to happen.

Mr. Robertson: Tom, a comment related to, this is Scott Robertson, diagnostic issues is that, especially with regard to things like the ADOS, is that, there's a great need, I think, also for diagnostic instruments out there that can address individuals across the lifespan, where things like the ADOS may not always work as well for picking up the diversity of, say, autistic adults.

So I think that's a thing to consider in there too.

Dr. Batra: Sally, this is Anshu, and I just, you know, was thinking about your

question in terms of does everyone use the same standard for diagnosing autism? And I think that's probably one of the most salient, sort of, issues here, is that, there really is not a clear consensus on, really, how to do -- you know, clearly diagnose autism because it is such a heterogeneous condition.

And I think that, you know, listen, we all have either have had children or individuals who are on the spectrum of autism, have been around, or treat them, work with them, and everyone looks different. Everyone has different, you know, phenotypes, but some core, sort of symptoms.

And so, you know, I think that's a very, you know, important question you raised, and I think that's, again, an important, sort of, issue that we should, sort of, highlight, I think, as we move forward, is that, there is no consensus. And, you know, how do we come to a consensus?

Ms. Crandy: This is Jan Crandy.

I think, too, that there needs to be included, some form of medical screen. It shouldn't just be observation, because we need to follow-up with these kids medically; what's going on with them? That needs to be part of a full diagnosis.

Dr. Burton-Hoyle: The standard assessment and diagnostics is what hit me when I read all through the public comments last night. I kept wondering, because as we are a new insurance state, mandated insurance, and that is how people will be assessed, diagnosed, is the use of the ADOS, and I agree with you, Scott, that more things, more heterogeneous across the lifespan, need to be developed.

But, to me, it's like, there's got to be a bottom-line somewhere if we're going to look at what it is we're doing, and what it is we're listening to, and responding to.

Dr. Batra: And the problem is that, you know, it's so heterogeneous and we

almost have to work backwards. We have to look at these, you know, phenotypes and then, you know, work backwards and see, what's the commonality, you know?

Ms. Abdull: Hi. This is Idil. I wonder what Dr. Boyle, CDC, thinks of that, because when people think of diagnosis you always want to get your cue from the CDC or NIMH. And I also wonder if people thought about, because autism, again, it's about behavior and behaviors about culture, and cultures so different.

So even just one example in our culture, to point, it's considered rude. So when they would say, is your child pointing? I would say, no, but I would think he was doing good, because he's not supposed to point. And if you do -- if we consider that, you know, it's not in our culture, so I just wonder if, and I know there are a 1000 different cultures, it would be difficult to have all of those, but just the basic, maybe,

African-American, Asian-American, something like that.

Is there something maybe the CDC and NIMH have on their Web site, or even the AAP? And then people can, sort of, take their cues from that in addition to the --

Dr. Insel: We're losing you, Idil. If you can --

Ms. Abdull: I'm sorry. Am I cutting off and on?

Dr. Insel: Yes, we lost the last part of that.

Ms. Abdull: Oh, okay. No, basically, I guess what I'm asking is that the folks from CDC and NIMH, and the AAP, where a lot of people that are diagnosing autism, not in the schools, obviously, but in the medical setting, can look at from the cultural point of view, because pointing is considered not culturally in many countries, and social skills, a lot of those things are different.

And if there is a way to look at

that, if there is a way, maybe, some things to be on their Web sites that could say, look at the patient, or the family's background and their culture, and how they view the behavior their autism is displaying, which, to some countries, might not be abnormal. It might be normal.

It was normal for me for my child to not point, or not to have imaginary skills, or play skills, that was normal. But in America, that's considered part of autism symptoms. What do you think, Dr. Boyle? Is there a way for you guys, when you're talking about act early, learn the signs, here are ways, you know, the ADOS, or the ways that most people use to diagnose, is there a way to comprehensively, nationally, look at that, and make it more culturally responsive, and even as another mom said, look at more medical stuff, because a lot of these children have medical issues.

They have, you know, diarrhea or

constipation. They have feeding issues. Just to look at the medical part not just the behavior part, which is mostly what the ADOS does.

Dr. Boyle: Well, Idil, this is Coleen and I think those a very, very important points and ones that we all need to be aware of. I know that, just in terms of the specific kinds of materials that we developed, you know, we've been trying to make all of the materials much more culturally sensitive and culturally appropriate.

I can't speak for the AAP in terms of the development of their tools, but I'm assuming that that's taken into consideration as well, but clearly, important points to continue to think about.

Dr. Insel: And I guess from the NIH perspective, speaking for NIMH, our interest is really going the other direction, to define this as a neurodevelopmental disorder that should have some diagnostic



biomarkers. We think of this as probably 10 or 20 different disorders, and what we don't have yet are the biomarkers to distinguish them, or even the biomarker that says you're in this general category.

You can think of it a little bit like if we were talking about fever before the era of thermometers. We just don't have any way of being rigorous about how we can define all the different pieces that go into this very broad category, so huge amounts to do, and we're at a very early stage in trying to define it.

And I don't think any of us believe that a questionnaire is ultimately going to give us the kind of rigor that we're looking for, because it will be enormously sensitive to context, to individual subjective assessments, and to culture. We need something that's far more robust than that.

Dr. Boyle: Yes, and these are topics that clearly should be discussed within

the context of the subcommittee work as well as the workshops.

Dr. Insel: I want to go back to where, you know, I think Lyn was taking us, which was the comments from the public that were expressing so much frustration around several aspects. So one of the things I think we need to do constantly as a committee is to make sure that we do represent the data that we've collected.

I know, because I've heard it over and over again, that all the research is going into genetics and others going into the studies of the environment, and it is important, I think, if you look at the documents that were handed out, which try to quantify this, to realize that there's some truth to that, that there's more investment in genetics than in environment studies, but it's not 99 versus 1 percent, at least according to that international document, it's about -- well the growth is in both.

It's very robust over the last decade and currently, it's about 57 percent for risk factors that are looking at it genetically versus 38 percent for environment.

So it's not half and half, but it's not 99 versus 100.

You know, it is important for us to be able to talk about the reality. The other point that Lyn brings up, which is so important, is the need to have a much more aggressive approach to the funding and the reality that we also have to make sure people appreciate is that, we're just coming off of the Recovery Act funding, which put a \$122 million into autism research, which is now gone, so we're seeing a big drop in what NIH is able to do, this is speaking for all of NIH, and we're facing a potential 7.8 percent cut coming in January with the sequestration budget.

So as much as we may feel the enormous need to do much, much more, and to

have RFAs, and to have the new ways of pushing quickly into this area where we want to do follow-ups, the reality is that we're looking at some potentially very difficult budgetary constraints and we'll have to figure out a way to make sure people understand what that looks like, and it's going to make the task really tough.

Dr. Batra: Tom, this is Anshu. I mean, based on what you just said then, I think it's even more imperative that we really look at what research has been funded and really, what has it gotten us? You know, how has it answered the questions that they were asked to answer, and really, what really the taxpayers are asking for, and what we parents are asking for. You know, how relevant is it?

Ms. Crandy: Hey, Tom, this is Jan Crandy. I would make a motion that we do have an environmental task force. I mean, I feel like the public is upset that we are not having that focus and I think that would let

them see that we are serious about looking at that. There are more and more parents choosing not to vaccinate their kids because that question really isn't answered to parents. We need to find that answer.

Dr. Batra: This is Anshu. I have to tell you that's probably one of the most common questions I get when parents bring their child to me is, what about vaccinations?

Should I vaccinate my child? And what caused this, you know? And, you know, I just shrug my shoulders and say, I'm not sure yet, but we're doing research on it.

Ms. Redwood: Hey, Tom. This is Lyn. I wanted to respond to the comment that I made about genetics getting the lion's share of funding, and this was based on our portfolio analysis, that question 3, risk factors, the total funding was \$81,000. Environment of that piece of pie was 5 percent. It was \$4 million 432. Epigenetics was 7 percent. Gene environment, which was 25

percent. And genetic risk factors was 63 percent.

So what's why I was saying that --

Dr. Batra: Where are you looking?

Are you looking in the global landscape?

Ms. Redwood: No, I'm looking in the 2010 autism spectrum disorder research portfolio analysis report, this is our most recent one, and I'm on Page 16.

Dr. Batra: Yes, I got it.

Ms. Redwood: So that's where I was coming from in making that comment. I would also like to second the motion that we do develop some type of task force to look specifically at environmental factors and also these novel findings in terms of trying to advance the science where we can identify those biomarkers based on those findings, and also work toward effective treatments.

Dr. Batra: I third that.

Dr. Birnbaum: Hello. This is Linda Birnbaum. Can anyone hear me?

Dr. Insel: We can, Linda.

Dr. Birnbaum: Oh, hallelujah.

I've been trying to get in for half an hour.

Dr. Insel: Sorry about that.

Welcome back.

Dr. Birnbaum: Thank you. I just wanted to make a comment about the 37 percent, Tom, that you were using for environment. I think that's environment written with a big E, meaning all kinds of environmental stresses, and I think that a lot of the concern from the community has to do more with chemical environmental causes or perturbation, and potentially, chemical infectious, or chemical nutrition, kind of, factors.

Dr. Insel: Yes, so we were comparing two different figures. I was talking about a number that came out of this global report, which actually looks at the number of publications.

Dr. Birnbaum: Right, but what I'm saying is, in that report, they're defining E

with a very big E.

Dr. Insel: Absolutely. Yes.

Dr. Daniels: Yes, Linda, this is Susan. We do even have a more detailed breakdown than what we put in the report, which, if the committee was interested in that, to see what exactly is in the environmental. I mean, we have it down to a grant-by-grant, but we also have even sub-sub categories.

Dr. Birnbaum: I think that'd be helpful.

Dr. Daniels: Yes, so maybe in subcommittee meetings we could share that information with you.

Dr. Insel: This is another place where, you know, as we've talked before across the entire portfolio, beyond funding, what we're really trying to find here are the breakthrough findings and seeing what can we point to to say, this is truly a risk factor? This is truly a cause? Or what have we been



able to eliminate, which is equally important?

So that will be one of the tasks for the subcommittee as they try to look at, what do we know? What do we need?

Mr. Robertson: Tom, this is Scott. I had a question related to the discussion right now on the task force. Is that something that's being proposed as a recommendation to the Secretary to do? I mean, I'm presuming it's not under the authority of the IACC. And on that note, is there room for, you know, "task forces" on other issues?

Because I know a number of folks out there that have had equal concern about lack of funding on some other areas, like, for instance, autistic adults that, you know, receive, you know, almost none of the funding, and there's been a lot of high concern about that as well.

It may not have been expressed as intensely in the comments, but it's certainly

felt out there.

Dr. Insel: No, I think that's why we really want the subcommittees to carry the water on all these kinds of issues and come back with proposals for what's the highest priority. We're not going to be able to do that in this conversation about the public comments, but we want to use the public comments as a starting point for that and then invite a much deeper dive on any of these issues in the subcommittees.

As I've said at the beginning, they're really going to be the working engine going forward and we're hoping that, of all of the things that each subcommittee is going to be addressing, you can identify a couple of areas where you think there ought to be some very focused work.

This sounds like one of them that people, just the environmental issues, with either a big or a little E that people want to do much more drilling into. And so that would

be one of the great things to do for this 2013 workshop.

Dr. Burton-Hoyle: And I think, this is Sally, the respect of the idea that there are many people concerned with the cause and all the various elements around that, the environment, vaccinations, and then there are many, many, many other people who nobody had time, I guess, to write in public comments around education, higher education, vocation, all those sort of things that will relate to better outcomes for individuals on the autism spectrum.

So I am so excited in the subcommittee to pursue those things that nobody wrote comments about.

Dr. Insel: Well, this is a very diverse community and part of what we want the IACC to do is to be, at the same time, very inclusive so that we get to hear from all the different perspectives, but also to set some priorities and to decide, of all the things

that you're hearing, what are the things that we can do the most about with the resources we've got.

And that's not an easy task, but we're hoping the subcommittees will start to chew on it in just the next couple of months.

Anything else from the public comments that you think we need to return to or talk more about?

Hearing none, Susan, do you have anything else for us?

Dr. Daniels: In the next few weeks we will be talking about setting up, or actually, in the next few days, I'll be sending out an email to the different subcommittees and try to set some dates for September that you can get together, probably on the phone, to discuss issues that are important to you.

And you can also let us know how long a phone call you might want to have to discuss all of these issues, to establish

various working groups, to work on the strategic plan progress update, as well as all of these really important issues that you've brought up, so be looking for more emails from me.

Dr. Insel: Great. Well, thanks, everybody, for your participation today and thanks to those who were listening in as well.

As we've said a couple of times, going forward, most of the work is now going to take place in these smaller groups, but we'll bring everybody back again later this year to look at the fruits of that labor and to make any final decisions, especially about the updated strategic plan.

We're adjourned. Thank you.

Ms. Abdull: Tom, could I make one comment before --

Dr. Insel: Yes.

Ms. Abdull: I just wanted to really thank and acknowledge Dr. Daniels. You are essentially, in your ninth month and

you're working, and I was off my feet in four months. I was like, wait on me, wait on me, so I really just appreciate your tenacity and just really helping us with all of this.

Dr. Insel: Here, here. Thank you.

Ms. Redwood: I agree. Tom, there was a motion on the table for establishing a task force, and a second, and a third, is that going to be voted on?

Dr. Insel: I want to refer that to the subcommittee to actually flesh that out so we know what's the parameter of this and I don't think this is the time, in the discussion of the public comments, to decide on this. Also, a number of people have dropped off. So let's really flesh that out and bring it back for the next meeting.

Ms. Crandy: Tom, this is Jan Crandy. Can that be a full committee vote though? Because I'm on the other committee and I do think it's critically important that

we have an environmental task force and to address these issues.

Dr. Insel: Yes, so --

Ms. Crandy: Maybe it should have been its own subcommittee then if it couldn't have been --

Dr. Insel: Jan, I think the best process will be in the subcommittee discussions that will take place in the very near future. This can be developed and really put together as a proposal for us to do in the coming months. But, you know, what I don't want is to, because we, by statute, have to have the update of the strategic plan, I want to make sure we get that done before we start on anything new.

Dr. Daniels: So in your subcommittees, if you have a recommendation for the full committee, then that can be voted on in the full committee.

Dr. Insel: Okay? Thanks, everybody. We're adjourned.

(Whereupon, at 12:37 p.m., the  
committee adjourned.)