

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

SUBCOMMITTEE FOR PLANNING THE ANNUAL
STRATEGIC PLAN UPDATING PROCESS

TUESDAY, MARCH 17, 2009

The meeting convened at 12:00 p.m.
in Conference Room A at 6001 Executive
Boulevard, Rockville, Maryland, Thomas Insel
presiding.

PRESENT:

THOMAS R. INSEL, M.D., IACC Chair, National
Institute of Mental Health

DELLA HANN, Ph.D., Executive Secretary,
Office of Autism Research Coordination,
National Institute of Mental Health

ELLEN W. BLACKWELL, M.S.W., Centers for
Medicare and Medicaid Services

STORY C. LANDIS, Ph.D., Director, National
Institute of Neurological Disorders and
Stroke

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

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

EDWIN TREVATHAN, M.D., M.P.H., Centers for
Disease Control and Prevention

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PROCEEDINGS

12:07 p.m.

Dr. Insel: Thank you and welcome to those of you who are joining us for this webinar. This is the first meeting of the subcommittee of the Interagency Autism Coordinating Committee to talk about the approach to monitoring and updating the Strategic Plan for Research that was released recently. I'd like to take the -- first I'd like to apologize for our getting a late start. We wanted to wait until we had a quorum around the table. We have that now and there will be a few people who will be arriving late but let's begin by introducing the members of the subcommittee. As you heard, this is Tom Insel who serves as the chair of the IACC and we'll move on.

Ms. Redwood: Lyn Redwood from SafeMinds.

Ms. Blackwell: Ellen Blackwell,

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Centers for Medicare and Medicaid Services.

Dr. Trevathan: Ed Trevathan, CDC.

Ms. Singer: Alison Singer, public member.

Dr. Hann: Della Hann. I'm serving as the designated official for this subcommittee.

Dr. Insel: Story Landis, the director of the Neurology Institute, will be here in a few minutes. She's delayed at another meeting. And then we also have on the subcommittee Lee Grossman from ASA who's not here and Stephen Shore who's also a public member who has not yet shown up. But given the fact that we don't have much time and we were scheduled to begin at 1:00, I think we need to go ahead and proceed. I'm sorry, we were supposed to begin at 12:00, thank you. The -- let's start -- Azik, if I can get you to move the slides forward, thank you - with what the reason for this subcommittee was, which comes out of the

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Combating Autism Act of 2006 which says that the IACC is responsible for developing and then annually updating a strategic plan for the conduct of and support for autism spectrum disorder research, including proposed budgetary requirements. So this is the effort that has to do with this annual update. When this came up as a topic of conversation for the IACC as you'll see in the next slide the discussion was that we needed to have a subcommittee that would -- oops, let's go back one -- that would look at a process for monitoring as well as updating the strategic plan. So the charge for us here is actually not to do the monitoring, not to do the updating, but to come up with a process that we can take back to the IACC about how we will do that and what it is that we would recommend as essentially a subcommittee that says we've thought about this, we've gotten some ideas and this is the way we think that the plan ought to be

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monitored and updated. So the task today is largely that, to come up with some consensus amongst us about what's the best way to get this done.

The next slide shows you who's on this subcommittee and before we go into the heart of what we need to talk about which is in the next couple of slides, let's just see whether there are any questions about what the charge is and what we're here to try to accomplish in the next couple of hours. Della, go ahead.

Dr. Hann: This is Della Hann and I've worked some with the staff of the office to sort of brainstorm and do some thinking ahead of time for this, and one of the things that we first landed on even amongst ourselves and I thought it might be useful for you all to think about too is what your expectations are for this process. I think there are different sets -- like I said, even among my staff members there were different

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levels of expectations about what they were thinking was going to be accomplished with the updating. And I think that might be useful to think about and get that out on the table so that -- to facilitate the conversations today. So that's what I have.

Dr. Insel: It's great to see this group so quiet, I must say.

Dr. Hann: Well, I guess one of the questions I have for you to think about as we go through the topic that Tom's going to take you through and so forth is to -- given that the plan is so recent, we just finalized it at our meetings in January or February, is to be thinking about for the updating process what that -- particularly this first year, what that's going to look like.

Given that the plan is so very new, and that the process that's envisioned potentially for this year, potentially even next year, may be different than the

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processes that you would think of for future years. So it's just something to think about because there was a tremendous amount of all of your efforts as well as a number of other people's efforts in creating the first version, and with it just being completed I think giving it a period of time in order to do some sort of assessment may be something to think about.

Ms. Redwood: You know, Della, the first question you had about what our goals or objectives were for today, I would like to see a strategic plan that is just so comprehensive, that takes in not only the federal money that's being spent on autism research, but also the private money, to make sure that we're not duplicating initiatives and to also really do a portfolio analysis of previous research in the last few years and what is ongoing research right now within either the Centers of Excellence and how many years they're being funded, and try to

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retrofit some of that data now into the strategic plan that we just developed to see how many of those areas we already have covered, and then we can look at where the gaps are in the plan, and then either look at some type of creative way of making sure that those gaps are funded. I know one of my frustrations in the past with the way that the first sort of -- I don't even know that you could call it a strategic plan for autism research -- was developed is that there was this great sort of initiative, but then the funding came in and it was driven by the scientists. And then those funded applications were retrofit back into the plan and so it did create these gaps. So I think it'd be nice to identify what our real important priorities are in research and make sure those are getting done and make sure this plan is very balanced with regard to treatment and, you know, mechanistic studies, genetic studies, because in the past I've

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felt as though there were areas that had really been overlooked, especially environmental and treatment research. So, you know, those would be some of my objectives for updating the plan.

Ms. Blackwell: I have a question.

I don't have my copy of the CAA with me today, but isn't one of our charges to give the plan to the Secretary? So it seems to me that it might be useful to solicit feedback from the Secretary on this first version of the plan and that might give us some direction in terms of where to go with Version 2.

Dr. Insel: We'll need to get a Secretary, but when we have someone in that job we'll -- I'm sure this will be something that will be part of their discussion. We already know that, as we mentioned at the IACC meeting, that the White House is putting a focus on autism and one would expect that the Secretary will -- if she gets confirmed

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will have this on her desk pretty quickly.

Ms. Singer: To that end, I was going to ask if there were any mechanisms by which we might be able to focus on the strategic plan in order to take advantage of some of the stimulus money? I mean, I think what the plan shows is that we are, if not shovel-ready, then beaker-ready, and we should be able to try to maximize opportunities for research under the expanded funding for NIH.

Ms. Redwood: And that was the same thing I was going to ask, Tom, if out of this \$8 billion stimulus package how much could we actually potentially get for autism. And one of the things that we didn't do the last time that I think would be nice to have is sort of a cost-of-disease analysis. You know, we have the Ganz study, I think it was out of Harvard, but that data really needs to be updated, and then if we looked at what the cost of the disease is to society I think

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it'll help us to then determine sort of a research budget. Like, what are we willing to throw at this to try to mitigate this disease and either help improve treatments for children on the ground now and the adults and possibly prevent the disease in the future. And I think it'd be important too to look at what type of research came in that NIH could not fund. You know, how many proposals were submitted in the past for autism research that were excellent, that were scored in the area where they should have been funded but we just didn't have the money. And then that'll help us to then go to Congress and say this is what we need and we can really I think come up with a little bit better idea with regard to a budget versus the way we did it this last time.

Dr. Insel: Right, I think we're going to circle back to many of these issues as we get talking about what we're doing because the landscape is very different than

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it was six weeks ago and the opportunities are very different. It's extraordinary that in this area we had just finished a strategic plan when a new \$7.4 billion for research dropped out of the sky, so there's an opportunity to really respond quickly and as you say, Alison, being beaker-ready helps a lot in this particular area. So there are some things that you probably know already which is there are challenge grants, there is an opportunity to fund research that hadn't been funded before, including research on autism that we hadn't been able to reach because the money wasn't there. But we have other things that are happening which we can't talk about here because it's a public meeting and RFAs that are still in the works can't be discussed because it could give somebody a jumpstart on them.

But stay tuned because over the next couple of weeks we expect that there will be even more opportunities in this area

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especially.

So I must say that we couldn't have asked for a better arrangement of events to have the strategic plan essentially finished in the end of January and to receive the stimulus package in the middle of February is just about ideal for us. So now it's a matter of getting everything out the door. And you can imagine because stimulus money has to be spent by the end of September 2010 so it's really 2-year money. The first year is half over. We have to move very, very quickly to get the funds out the door so they can be spent in 2009. And so whatever we're going to do is likely to be public I would think by the end of March and that's really where the NIH has been pushing so much. Ed, anything you want to add?

Dr. Trevathan: Yes, it seems like there's a lot of agreement. I agree with everything that's been said, and just to echo what Lyn said, I do think it would be helpful

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for us to, as we look at gaps, to look at what's needed in terms of determining cost across the life span scenario that's really fairly important. And if this committee is going to be addressing gaps, at least in terms of areas where we don't feel like we've addressed in the previous plan, one question is how do we do that, can that be accomplished with existing or previously set up workshops and work groups, or is there other need.

So for example, if we look at the needs of young adults in transition with autism we really don't know enough about what are the specific targeted health promotion needs of that population if there are any, and I would assume that there are some. So we were looking at this at our center the other day. We have programs for people with intellectual disabilities, spinal cord injuries, all sorts of other potentially disabling conditions, and we know that

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there's specific needs that those populations have. Some are at increased risk of obesity, some have high rates of smoking, depression, substance abuse, and we can have targeted health promotion and intervention activities and communities.

I don't think we even know enough about autism in young adult and adult populations to know whether there are special needs. So that could be an area of research that we want to explore. So in terms of the process, how do we approach these questions that may come up at our level, how do we task the workshops and work groups to best address some of the issues we have, I guess that's a question that I have for you.

Dr. Insel: I want to mention to those on the phone that Dr. Story Landis has just joined us. Story, we're in the middle of just talking about expectations for the group. It's probably worth going onto the next slide which describes part of what we've

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been talking about right now.

What is it that we ought to be thinking about and how are we going to get at, as Lyn says, this comprehensive picture of what's being done and how to identify the gaps of what is not being done. These were some items that the office came up with, but this is really just to get you starting to think about what we need as we begin to do this, and then we can think about how we'll get the information.

Ms. Redwood: Tom, I would like to know a little bit more about the centers and you know, historically what type of work they're doing, how they're funded, and what's on the ground now with both the intramural and extramural programs here at NIH. If there could be some type of briefing maybe at our next IACC meeting? And then you know, to have the staff go back and look at what's funded and see where that would fit into the strategic plan that we just developed. I

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think that would be helpful.

Dr. Insel: We have not actually done anything like that at the full IACC meetings, have we? We haven't had the ACE centers or the intramural program present. Okay.

Dr. Landis: So one of the things that came up with our Udall centers -- we had 13 of them for Parkinson's -- is the Parkinson's advocacy groups and foundations and research groups thought it would be extraordinarily helpful to have on a website lay language summaries of what's happening in those summaries, and what kinds of research and what accomplishments. And I think that might be some -- a way to inform the community and even the research community about opportunities that the centers might present for collaboration. So I don't know if such a write-up currently exists on the website.

Dr. Insel: I don't know, I mean

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it's one of the things we could look at. The other -- certainly there's plenty of time. The next meeting is on May 4 and I'm sure we could get -- I don't know that we could get all the centers there, but we could have someone perhaps give a summary of what's going on at the various centers and then we could have someone from our intramural program give a quick overview of what's going on.

That's a relatively -- to the total investment from NIH it's a relatively small piece of it, but it's one that is very visible and it would be an easy way to capture a lot of things at one time.

Ms. Redwood: So what's the large piece?

Dr. Insel: It's a real mix. I mean, most of what we do are R01 grants, so they'll be -- if you think about -- I think the way the numbers break down, I believe it's at \$112 million. Is that what the RCDC

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total is, something like that? And I think the centers are going to be \$22, somewhere in there, the low \$20's. So it's less than 20 percent of the overall investment. So you've got -- it's individual research project grants they're driving at.

Dr. Landis: So the cool thing about RCDC which for those of us who have been through the change was not a cool process at all, is that you can go on to the NIH website, you can Google it for NIH disease funding. You'll come up with RCDC, you'll come up with a number for 2008 and you click on that number and it will list all the projects and the dollars and the people that are identified by this computer-based accounting mechanism as autism research.

And the Parkinson's Action Network just had an effort in D.C. and they actually had computers out for people who had come to D.C. to go and talk to their senators and Congress people where they were letting

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people look. You know, what's in my neighborhood. So you can find out exactly what is classified as autism research by going through this RCDC website. It's pretty extraordinary.

Ms. Redwood: So autism is already in there?

Dr. Landis: Yes.

Dr. Insel: So, to be clear, it's autism, not autism spectrum disorder. So it's -- but the definition of autism is also available so you know what it is was meant. So it's -- and that's why, what Story was saying about how it wasn't so cool for those of us involved was that the numbers changed from what we had been calling autism in the past. In our case, they changed quite a bit.

And the -- now we've got one consistent definition across all of NIH and everything is available.

Dr. Landis: Same with accounting which at NINDS we used to account differently

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than NIMH accounted, so everybody's accounting is done the same way. What was particularly painful was coming up with a fingerprint for what would be classified as autism research, and I think for many of the fingerprints it took months to get consensus and then they'd run the fingerprint on the grants, see what came up as grants that were classified, go back, re-fix the fingerprint.

And it's not perfect by any stretch of the imagination, but it allows NIH and people throughout the country to actually see what we're spending according to that definition and how much it is and where it is.

Dr. Insel: This gets to the first question about types of information needed and sources of information. So what I'm hearing from you is that one kind of information you'd like to see is dollars. You'd like to know how much money is being invested in autism and Lyn, you started off by saying that you thought it would be useful

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to have a comprehensive picture, not just NIH, but public and private and DoD. So in terms of sources of information, RCDC will provide the dollars for NIH for autism and it's easy. What it doesn't provide is the breakdown of the overall autism number by the strategic plan.

So if you wanted to say for the strategic objective question 2 and the short-term objective C how much is going into that, you can't -- you'd have to do a fair amount of work to get that off of RCDC. What you might want is to have someone actually look at the NIH portfolio and essentially code it or tell you what's going into the strategic questions. So what are we spending on Question 1 and the various objectives, short-term and long-term. Now, the information that would be available would be 2008 because the 2009 information won't be available till probably February or January, Della? January. So this could be done for 2008 and

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you just have to understand that that's our baseline because that was done before we had a strategic plan to look at. But it might be very helpful to have the baseline numbers. And you remember we did this about a year ago, but we did it with respect to the four themes that we were working with, not the six questions. There's a pretty good mapping, but it might even be better now to map it at a more careful level with respect to the specific topics and objectives that are in there. So that's the kind of thing that if the group felt would be really an important kind of information to have, and that did want to pull it off in that way we can make that recommendation and make sure that this gets done.

Ms. Singer: We did that exercise a year ago. The private funders also participated and I know they contributed data. Do we still have, or can we get private funding 2008 data and try to map that

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onto the plan as well?

Dr. Insel: What do you want to do? I mean, if you think that's important. We don't have any leverage over those groups, but we can ask, and they were cooperative a year ago. I think they may still be cooperative.

Dr. Hann: That's absolutely true, and I think even for some of our sister federal agencies too. We can ask. We don't have the same amount of leverage as we do for the NIH to be able to do that. The other thing to keep in mind too because I remember -- I came onboard right around the time that that was happening last year, and I do remember bits and pieces of that prior coding exercise, and I know some people were -- or some other organizations were okay about, well, I can tell you the amount of money I spent, but I really don't want to give you my project by project listings. They felt that that was more within their organization.

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They really didn't wish to share that level of detail. So I just put that there to you that we could get varying responses from people with regard to this in terms of level of detail as well as even willingness to provide us the information.

Dr. Insel: Can I follow up on that, because Lyn you had said that at the beginning that you thought it was useful to have individual listings so you'll know, for instance, if someone is funded three times to do the same thing, or if there's a lot of overlap. Do you think we should push on this and try to make sure? Because I'm sure they would send us the total dollar figure. It's a fair amount of work for them to get the individual grant listings and to code them. They must have the individual grant listings, but doing the coding may be more difficult. Do you think this is important enough that we need to --

Ms. Singer: I think they all make

that public except for the Simons Foundation.

I mean, just looking at this list, does ARI make its list public?

Dr. Insel: Let's go to the next slide. Right there. So those are the private funders. When you say they make it public, they make what?

Ms. Singer: Autism Speaks posts it on its website.

Dr. Insel: But posts what?

Ms. Singer: The names of the grants, the researcher and the dollars.

Dr. Insel: But could we use that to -- I mean, so who would do the mapping of this onto the 32 initiatives or whatever we have in the strategic plan?

Ms. Redwood: Can your staff do it?

Dr. Insel: I don't think they would know enough about -- you mean, can their staff do it?

Ms. Singer: Who did it last time?

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Wasn't there a meeting of the program officers?

Dr. Insel: There was some -- there were lots of conversations between the program officers between Autism Speaks and NIH, but at the end of the day Autism Speaks I think would have to give us that kind of map because we won't know, besides the PI and the title we won't know what's, you know, if it's 30 percent, or 20 percent, or how much of it's actually going into any particular topic.

Dr. Hann: The last time, the organizations themselves did the coding. We did the NIH.

Ms. Redwood: To answer your question Tom, yes, I think it'd be important information to have. I even think with Simons Foundation we could probably sort of guess.

Ms. Singer: They -- the Simons Foundation as I recall printed it out but

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then collected it up. So I think they were willing to share it in the meeting, but they didn't want it to be made part of the public record. Is that right? Does anyone else remember that? They collected up the sheets again, so. They're a private. They don't have to -- I don't know.

Dr. Hann: Several of the organizations actually did that with us. They shared but then they pulled. They didn't want it openly shared. And now that we have a deeper and greater appreciation for our FACA responsibilities, I don't think we could do that anymore.

Dr. Insel: So what does that mean, Della? Does that mean that we would -- anything that we're given would have to be in the public domain?

Dr. Hann: Yes.

Dr. Insel: So would that preclude them from sharing the information?

Dr. Hann: I don't know, I can't

speaking for them, but I -- just in terms of interactions I've had in the past with some of the -- even some of our sister federal places, they're not overly eager. So I'm just putting that out there just so you're aware.

Ms. Redwood: Let's try, and if it doesn't work --

Ms. Singer: Exactly.

Ms. Redwood: -- we'll report back that they wouldn't give it to us.

Ms. Singer: I was going to quote John Shestack and say, you don't ask, you don't get. So I would try.

Dr. Insel: So we will not only ask, but we can also go forward with some real guidance about precisely what we need and how we want it done. So it will hopefully harmonize well with whatever's being collected from NIH. What about CDC, Ed? Is that going to be a problem?

Dr. Trevathan: On the surface I

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think not. I mean, if you get into areas where there's active what we call in CDC primary prevention efforts then it's tough to know. So for example, is prevention of fetal alcohol syndrome autism? Well, yes, sort of.

When we prevent congenital rubella syndrome, you know, some of those kids would meet diagnostic criteria for autism, is that autism? So those questions will come up. So I think that probably having some standard definition of what we're talking about and then having -- allowing agencies to explain the way they came up with their numbers would be useful. Because some of those issues are important, but I don't think that's what this committee is referring to. But I don't see it as a problem, I think we just need to be very clear as to what exactly the data are that the IACC wants.

Ms. Blackwell: I think that would be really helpful to us as well because we have a lot of research at CMS on topics, for

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example, the drug service workforce, housing, that obviously impact this population but you know, aren't directed specifically at people with autism. Maybe they're directed at people with developmental disabilities. So for us it would really be helpful if there is some definition so we know, you know, where does the overlap stop.

Dr. Trevathan: It would be nice for us to know what's out there that does apply to autism even if it's not all autism.

I mean, I think that -- and that's I'm sure an issue you all struggled with at NIH, but some of the activities we have in populations dealing with intellectual disabilities and communities. I mean, some of those folks meet diagnostic criteria for autism and some of those services are helpful and some of those research projects are helpful. So how to deal with those types of things that are partly autism, but not dedicated to autism. So we can capture them, but not overstate

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what we're doing I think would be useful.

Dr. Insel: So we can give you guidance on that. I mean, I think that's part of where the office can be helpful is to clarify what we're looking for and to remember that at the end of the day the purpose of this is to know how to modify the strategic plan and to know how well we're doing implementing. So if it doesn't map onto the plan it's probably not going to be all that helpful, unless there's a way you can identify that little piece of it that does and then account for that. Alison?

Ms. Singer: And maybe one way to sort of put some parameters around it would be to focus on CDC spending that falls under the auspices of the Combating Autism Act, because didn't CDC get money specifically under that act? And maybe that's where we could start with accounting specifically for those funds.

Dr. Trevathan: I don't know about

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others. Our funding from that act was fairly small or limited or very focused. So that's the easy part, I mean, that we can give you tomorrow. It's these other areas that don't necessarily fall under the Combating Autism Act that requires a little work to sort through.

Dr. Insel: So we're talking about dollars and trying to figure out how to code this and who we need to ask. Is this list the list that we need for potential funders?

Is there anybody else - I'm sorry, stay with this slide. Is there anyone else who ought to be asked about their investments that we're not showing up here?

Ms. Blackwell: Housing and Urban Development.

Dr. Insel: So HUD?

Ms. Blackwell: Maybe Social Security.

Dr. Insel: The questions I'd have, Ellen, that for HUD and Social

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Security, do they actually have a research - that would be aligned with what's in the plan?

Ms. Blackwell: Well, as Alison said, I think maybe it's just worth asking.

Dr. Insel: Anyone else that we ought to be thinking about?

Ms. Blackwell: What about the Office on Aging?

Dr. Insel: Office on Aging.

Ms. Blackwell: Or the Department of Aging, I'm sorry. I mean again, they may have initiatives to people with - older adults with developmental disabilities that overlap some autism efforts. I just don't know.

Ms. Singer: Wouldn't that be more services than research?

Ms. Blackwell: It could be research. I don't know.

Dr. Insel: Most of those agencies as far as I know are really funded for

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providing services and funding them, but not
- they're not discovery-based.

Dr. Trevathan: Well this might be
the same issue, but the Administration for
Children and Families, whether or not some of
their services have a research arm or not.
I'm not sure. I think that they may have,
but it may be worth asking.

Dr. Insel: We can check. Yes.
Anybody else?

Ms. Blackwell: What about AHRQ?

Dr. Insel: Yes, AHRQ. Good.
Okay. Now that they have a lot of funding
for comparative effectiveness, it would be
interesting to see if they are planning to do
anything in this arena. Are we leaving out
anyone else? Any of the - NCCAM. Yes,
they'll be part of NIH, so. Is there any
private funder that we might be overlooking
here? These are only U.S.-based. I mean,
there are lots of UK and others.

Ms. Redwood: Does the Flutie

Foundation or is that predominantly services?

Dr. Insel: Flutie is services.

Okay.

Ms. Redwood: Does IHS do any research on Indian populations?

Dr. Insel: No, not in this arena.

Other private groups.

Ms. Redwood: CARD, the Center for Autism-Related. I know they funded I think a couple million just this past year. So are they on there?

Dr. Insel: No, they're not.

Let's add them.

Ms. Redwood: I would add CARD.

Dr. Insel: Yes, okay.

Ms. Singer: Are they part of ARI or independent?

Dr. Insel: Okay.

Ms. Singer: They're independent.

Dr. Insel: CARD, okay. Anything else? So these would be the groups we'd go to to get this comprehensive picture. We'll

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come up with a template for the kind of information that's needed. You comfortable with the office going out and soliciting this on behalf of the subcommittee to get the information? We'll have to go - well, we have to - at this point we're coming up with a plan for how we will do this, so. Right. But we need to make sure that the subcommittee is recommending that the office becomes the main vehicle for this.

So that's looking at money. What about other types of information that you would want in terms of either monitoring or updating? What else would be important?

Ms. Redwood: Tom, does NIMH have an office that does sort of a research portfolio analysis with regard to impact of research? Because I think it would be really important to not just look at where the money went, but the outcome. And we may be too early in the process to really do that, but I think there's been criteria established where

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you can sort of score research whether or not the outcome was a published article, or there's certain criteria. So I want to know how much bang we're getting for our buck. You know, if we funded a million dollar project and we didn't even get a good paper out of it, then you know, we need to be somewhat more critical with regard to what the outcome is on the other end.

Dr. Hann: I just want to add to that. There's actually an additional set of tools that should be coming online hopefully in April, so not too far from now, building on the database that Tom and Story just mentioned to you, that RCDC tool. There's going to be an additional feature added to that such that projects that are listed - like if you hit on autism and then you go into the project listing, that a subsequent version of that, we call it Reporter, will allow one to hit the PubMed database too. So for each of the grants that are listed you

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will also start to be able to see the publications that resulted from that grant, assuming that the investigator has cited the grant in their publication which we're working on that too. So that's coming online and that will become available in hopefully April to help facilitate the type of analysis that you were just speaking about. So that if you had several grants that had been up and going for a period of time because it's usually not possible to publish within one's first year, so you want to give them a little bit of time. You can start to see what the publications are that are resulting from those grants.

Ms. Redwood: Is there a specific office here at NIMH or over - I think the whole Institute back maybe two years ago they were establishing an Office of Research portfolio analysis and they hired somebody. I remember reading about it. What happened?

Dr. Insel: Right, so there's a

whole program around portfolio analysis that was put together. It's morphed into different elements, but this is NIH-wide, and what you're asking is a little bit different than what they're doing. They're looking at kind of NIH-wide initiatives and NIH-wide evaluations, and also tool development. So these things that Della's been mentioning are part of the kinds of things that NIH is putting into play. I thought you were asking a little bit more complicated question, which is essentially how do we measure impact. And the easy part would be counting the papers that come out of grants, and we certainly can do that, and that is the kind of thing that these tools will be very helpful for. What - I think Lyn, you were the one who brought up at the last meeting when we talked about putting together the required report about initiatives - or what's the term, research advances, summary of advances - that you wanted to know. So how many of those are in

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any way coming from the funding that we're supporting? Because if it turns out that you review the literature and that of the 20 most important advances only five of them came out of the funding that any of us are involved with, you've got a problem, right? You want to know what we're not doing right. So is there a way to get that done? I mean, certainly we'll do the summary of advances each year as required, and that's one way of looking at what the science is producing, but how will we align that with this, with the opportunity to say oh okay, so we put X dollars into this area and a year later we've got these, or two years later we've got these kinds of advances to report?

Ms. Singer: I also think we have to move away from looking at number of publications as our outcome, or even number of citations. I mean, I don't think this committee was formed under the CAA because Congress to maximize the number of

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publications. I think we need to find some way to measure improved health outcome, or improvement in quality of life that results from this research. And I know that that's very hard to measure, it's much easier to count publications, but I think we won't be looking for the right things if we continue to measure our success based on publications.

So maybe we should spend some time talking about what type of metric we could employ to really measure what it is that we're here to do, which is improve people's healthcare and maximize their quality of life. Maybe Ellen has some - you know, I'm putting you on the spot, but I would hope that Medicare and Medicaid you have some metrics by which you measure the improvement in people's actual lives.

Ms. Blackwell: Well, I think it's really - I mean, it's sort of what Tom talked about earlier. It is, you know, how do you evaluate the effectiveness or the efficacy of

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a paper compared to what happens in the real world, and I don't know the answer to that, Alison. You know, in terms of Medicare coverage we do have a pretty straightforward process in place to decide, you know, whether or not an item or device or procedure is appropriate to be - is reasonable and necessary in terms of coverage, but on the Medicaid side it's much more difficult. We don't, you know, there's a lot of latitude in terms of what states cover and in our statute, you know, in terms of how many community-based services. States can cover almost any procedure that would permit a person to function more effectively in the home and community-based setting. So we're getting into some pretty tough areas. The opposite side of that coin to me is if there's something we shouldn't be looking at. I mean, I don't know.

Ms. Redwood: Could we not go back - and Alison, you touched on this briefly -

at what our overall mission and goals were.

And then also analyze the research for whether or not, like you were saying, did it somehow reduce morbidity or mortality rates, did it result in some type of new treatment.

Have the numbers for autism started to decline, you know, based on either identifying some type of environmental risk factor, or do we have improved outcomes either in cognition or speech from different therapies that we've identified or medications that were successful. So I think, I mean it's not an easy job, but I think we could do it.

Dr. Hann: This may not be helpful. I'm trying to be, but it may not be. So, at the beginning of each chapter you all gave a lot of thought to some basic questions that leads off each of the chapters. And so just picking up for Chapter 1 which is When Should I Be Concerned, what are the early warning signs? Are there

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typical characteristics that are part of an ASD diagnosis? How much variation is there in symptoms and severity associated with ASD?

Are those the kinds of questions essentially that we're looking to see answered by the plan, and could those then be used as some sort of scaffolding for the kinds of things you're talking about? Have we made progress?

Do we know - I mean, I'm just using this, again, as a heuristic to talk about, but do we know? Do we know now what the early warning signs are vis-a-vis some of the research that might be going on with the plan and so forth? So that might be another way for you all to help get a little traction.

Ms. Blackwell: And I think that we need to take a step back for just one second and go back and look at this plan and even make a recommendation to the committee that this is in fact the format that we want to use moving forward. You know, that we're still all okay with having this introduction

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and having these questions and the mission and vision statement are okay. Isn't that part of our job as a subcommittee to make a recommendation to the committee that we should stick with this, or not?

Dr. Insel: Yes. I think we'll get that, Ellen, in terms of how we want to update and what the next draft might look like. But I want to make sure we resolve this issue around the types of information needed because what I've heard now, everybody is in agreement that we need the dollars, we need the investments about - particularly for new research going forward, and we need to know how that aligns. I've also heard this interest in impact and I've heard it in two different ways. Maybe it would be helpful to separate it out - we sometimes do this in NIMH - between what we call outputs, like the number of papers, number - sometimes we look at number of awards, you know, things that are easy to quantify, and outcomes which have

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much more to do with the sorts of specifics that are in the plan. Like are we able to identify a greater number of children at an earlier age based on some breakthrough, a biomarker or some predictive diagnostic, something like that which might be helpful because the outcomes come much later, so they follow long behind the outputs. What you don't want is to create a literature of a thousand papers and have no impact on public health. So we need to monitor both and one might think if the job here is not just updating the plan, but the committee wants to get involved with monitoring, we have to think about how would we get that information, and the best way to be able to do it. The papers are probably fairly straightforward I would think. You could count, you know, you could easily do that and it could be tied into what we're doing each year for the - the summary of advances. But the summary of research advances is a little

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different than outcomes.

Ms. Redwood: Tom, just a question. When you fund research at NIH, is there a requirement in your contract with the researchers for a published paper, or is it just that they give a report back, and I assume that report would be public since it was federal money that was spent. Could we get copies of the reports? I mean, I would love to read them.

Dr. Insel: There's an annual progress report that is required, and then there's a final progress report at the end of a funding period. There's no requirement for a grant for - because it's a grant to an institution. It's different than a contract.

So with a contract you have a particular output, so you may need some deliverable. There's no precise deliverable with a grant, like an R01 or an R21 grant. So it's not a requirement. If somebody wants to get refunded after they've been funded for five

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years and they have no publications very unlikely that that would happen, but it's not - it's certainly not a requirement.

Ms. Redwood: But what about the final reports. Those are public, right? No?

Dr. Insel: None of that's in the public domain. Right.

Ms. Redwood: You're kidding me. I know we've been able to FOIA that stuff before.

Dr. Hann: You can FOIA it, but it's not something that's publicly put up on a website. So that's - I was trying to make the distinction of that. So, those are not like readily put up for the public. And there's a lot of reasons for all of that that I don't need to go to, but that's the answer to your question.

Ms. Redwood: Can you guys get that for the research that you funded for autism? Can you get the final reports?

Dr. Hann: The program officers

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look at that information as they go through to do their evaluations each year, they look at the progress to make recommendations about whether or not they think the project should continue or not. So if someone's really fallen off the wagon and isn't performing, then there may be a reason to stop the grant.

So, those progress reports are used.

They're used to determine continuation essentially of business, and then the final reports, there's been a big effort the last three to four years, actually, for NIH to gather the final reports. Folks often are not happy to do a final report because they want to get busy on their next project, so getting that tied up and come back to our system has been a little bit more of a challenge, but we're working on it.

Dr. Insel: But even if we had it, I'm not sure it would be as informative as the manuscripts because it's the data themselves are going to end up in the

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published form, and what we've worked very hard on in the last five years is ensuring that anything that is published with public funds becomes publicly available. And I think it's now at 18 months or nine months, what is it, six months? What's the timeframe. Everything goes onto PubMed Central. So you should be able to access any publication. And those publications in turn are tied directly to grant numbers. So you could actually put in a grant number, get not only the reference but the actual publication downloaded with the push of a button.

Dr. Landis: And that will be part of Reporter when it's finished. I would say NINDS has been struggling as we look prospectively at trials we might do and retrospectively at trials we have done to try to figure out what their impact has been. And this is not an easy thing to determine. First of all, there's the - if it's an intervention, was the intervention successful

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or not, and if it didn't work, have people stopped doing it and is Medicare or Medicaid and private insurance companies no longer reimbursing for it. If it was successful, how long has it taken to be adopted more broadly into the community and are there things that we could be doing to ensure that in fact it would be adopted. And I think for any intervention it looks to be promising for autism and for which there is then solid scientific evidence. An issue will be how quickly is that adopted because if there's no adoption then there was no impact of that intervention study. So I think there are a lot of complexities there.

Dr. Insel: So, let me just summarize where we are at this point. So we've talked about the need to put in dollars. We've talked about the need to kind of get our hands around impact in some form, and some of that would be these outputs of manuscripts, potentially final reports or

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some description of what came out of investments made. Some part we hope will have to do more with outcomes, and actually maybe even at some point creating a sort of dashboard based on the strategic plan and the things that we said in the plan we most wanted. Like you were saying Lyn, going back to Square One and saying this is what we were after when we put this together. Are we getting it? Are there other pieces that we ought to be following in terms of deciding to update the plan and how to update the plan that might not have anything to do with what we're currently funding, may not even involve autism yet, but something - so a new discovery that comes along, a new technology, something that is out there that could have a huge impact on autism, but no one in the autism world is working on it. Story brought up stem cells, I think, at the last meeting, that opportunity to use induced pluripotent stem cells which could revolutionize this

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field. People weren't in there, weren't doing it. And how do we collect those things that are important because they're not yet being used and need to be used to update the plan.

Ms. Singer: I think what that is going to require is us to be less afraid of qualitative information. I think we've always been more comfortable with metrics where we could count. But I'm thinking for example of Dr. Mark Bear from MIT who presented at the IACC meeting I think last year whose work started looking at the optic nerve and then he really revolutionized Fragile X. And now his work is moving into clinical trials. There may be a pharmaceutical intervention to reverse the symptoms of cognitive disability with regard to Fragile X. So when you think about revolutionizing the field and impacting people's lives, I mean I think that's a great example of one that was not even on the radar

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screen because the work was being funded by -
in the field of ophthalmology and now it has
tremendous potential. So I would just urge
the group to spend some more time than we
might normally looking at qualitative data as
opposed to what I think we've been more
comfortable with which is the quantitative.

Dr. Insel: How do we do that?

Ms. Singer: Well, that's the
tricky part. But I think you know, this
group has a certain amount of expertise. I
mean, the people who sit around this table
basically spend most of their waking hours
reading the research or doing the research or
funding the research. So I mean I think this
is a smart group and I think if we - the way
we're working on the annual list of research
- what is it called? Summary of advances in
research is a good example of a good method
where it's casting an incredibly wide net
with many, many buckets and deep buckets,
more data than I think any of us really want

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to wade through. So thank you Della. But I think that's a good way of doing it because that is the expertise that I think we do have around this table and at the broader IACC.

Ms. Redwood: The other thing along those same lines is when we do have a research finding that you were pointing out that is highly significant what do we do to follow up on it? For example, the study a few years ago by Diana Vargas with finding neuroinflammation in the brain. There's been a couple of little studies after that, but to me that's hugely important and it's a big target for potential intervention and mitigation if we can find out what's causing this neuroinflammatory process. Is it something that we need to try to support, or is it something we need to blunt, and it's like we have findings like that that come out, but then they just sort of fall into this black hole where nobody really follows up. And so if there's a way we can identify

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these things that we think are really new, emerging science. I think the findings now with mitochondrial abnormalities in children with autism is hugely important because again, when we can identify those specific types of comorbidities, then we can apply targets for treatment. And so if there's a way that we can really focus when we identify what the top 10 research advances were this year that we're going to include those somehow in the strategic plan to be continued. That might be a way to update the plan to make sure that we're following the most promising leads in research.

Dr. Landis: One of the most important things I think is that if there is an unexpected finding to make sure it gets replicated. Because until it's replicated other investigators won't actually pursue. It will be something that's fringe and doesn't have the kind of solidity that people who are moving into an area will want to know

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about before they invest three months in writing a grant, or three months in setting up a new assay. So I think replication, and one question is whether or not as part of the plan and research initiatives this group would want to recommend strategies for replication. So for NINDS - I'm sorry to keep harping on lessons we've learned - in spinal cord injury people will publish a wonderful recovery of rats with a spinal cord lesion, and they'll have 10 rats and 10 controls, and people want it to go to clinical trials and it turns out we actually set up a center to replicate those studies, and nothing that came out, out of three tries, nothing that came out of those 20 rat studies has actually been replicable under controlled circumstance. And so we've not gone forward to clinical trials which could have taken years and many patients. So replication and how - I mean, maybe NIMH is already thinking about what are the most

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exciting things and do we need to have a mechanism to make sure they get replicated. And the data are solid enough to pursue in a more meaningful fashion.

Dr. Insel: But how do you even get those unexpected findings, or the report on inflammation in front of the committee? Let's say they are replicated. So what we want to do is figure out how do you update the plan so that the 2011 version will add to it the importance of doing a study on mitochondria, or studies on inflammation, whatever it happens to be that you decide. Maybe it'll be epigenomics will be the hottest thing going by then. What's the process by which do that? Does this group sit around and say hey, this is a very cool paper that's come out, and hey look, somebody else replicated it and then we make a recommendation? Do we want to use the IACC meetings to showcase some of the science that we think is going to be most important like

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we did for Mark Bear? How do you see this happening?

Dr. Trevathan: I could see using some of the IACC time on this, but at the end of the day the real targeted scientific expertise is more down in the workshops, work groups. So somehow it seems that these are questions we should task them with, but there needs to be a mechanism that's sort of fluid, ongoing where we have these workshops that identify these topics and then they can shoot them up to us.

I don't know if that process is already in place, but I don't think we have the breadth of scientific expertise on the IACC. I mean, many of us are busy running pieces of agencies now and aren't doing this research as much as the guys that are - the folks that are down in those workshops. So how to utilize their expertise to get this information I agree it's a critically important thing for us to do.

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Dr. Insel: So when you say "workshops," you mean -

Dr. Trevathan: Or the work groups. I may not be using the right term.

Dr. Insel: Well, okay. I was thinking, you know, where you often hear about this would be at a national meeting, or an international meeting, or some scientific group that gets together. And that would certainly be one way to do this is to use IMFAR or one of these organizations to help at least put a focus on what's new and what's hot. But often, as Story mentioned, the thing that's most exciting doesn't - you know, it's an abstract that doesn't get published because it can't get replicated even within the person's own lab. But still there's got to be some way that we can keep this plan on the cutting edge. Actually, we want to keep it in front of the cutting edge. We want to be telling people what they need to be doing in 2012 and -13 by 2011 if we

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can. Because we want to be driving research.

Dr. Trevathan: Well, is there a mechanism, Della, with the way we currently have our workshops set up? I'm using the correct term, right? To have them tasked with doing just this, is identifying hot topics, unexpected results from research that they think the IACC needs to be aware of, and that we too can ask them questions, you know, and get expert response back.

Dr. Hann: Well, at this moment in time there is no process in place, and that's really what this group must just sort of struggle with and come up with an idea of how to do that. Last year, when last year we began this process there were a series of work groups, or workshops that were convened to do all of that. Those were one time events. So they've come and they've gone. That's one modality by which to do the kinds of things that you're talking about. So that would be - if you wanted to have that put

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into place that would be a recommendation that would come out of the subcommittee.

Ms. Singer: I was also going to raise the idea of IMFAR which is in May and a lot of the publications seem to be held for release at IMFAR. So we get a lot of new data in May, so maybe the committee wants to consider recommending that we hold these workshops in September so that a little more time has passed, and then really organize the workshops around the six questions. So maybe it's two days of scientific workshops where we're asking people to come and present what's new, what's on the cutting edge, sort of using the template of the strategic plan, and then move forward from that and then present that as the data from which to - this committee then uses to recommend updates to the strategic plan.

Ms. Redwood: Can we have - can this committee, as we're a subcommittee of IACC, correct? As a subcommittee of IACC can

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we establish a work group? No? We can just do workshops, that's it? Workshop. I wonder about a conference, if you know, that might be a way to sort of try to update the science annually for the plan.

Dr. Insel: What do you think about this idea of whether you call it a conference or workshop, tagging it to the six questions?

Ms. Redwood: Yes, absolutely.

Ms. Blackwell: I like that idea.

And I thought that the work groups, the expert work groups, and we can convene expert work groups, they were really helpful. I mean, we did invite some of the best minds and we did get some really good feedback. So now we have something to show those folks and we can say okay, what's here, what do you think needs to be updated, and where do we need to be going. I mean, that would be very helpful to us as a subcommittee and as a committee.

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Ms. Redwood: I wouldn't know that we would need to replicate the whole process again, but I think maybe just bringing back the workshop chairs and maybe select maybe three or four of the top people from those specific committees and also let the IACC be a little bit more involved in the process of appointing the work group members. Also, something Della, I had asked awhile ago if it would be possible because somebody will send me some exciting new research that's just come out and I want to share it with the committee, but there's really not a good mechanism in place to do that. I almost wonder whether or not once a month we could almost have like a PDF that would be sent out, sort of like a journal club, where there's certain new research that's shared with the committee on a monthly basis and that might also make it easier for us to identify these annual updates. When it comes to the end of the year, we've already got all

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of our monthly, you know, articles that we thought were cutting edge and important and identified from this sort of journal club type of mechanism.

Dr. Insel: Is there any reason why we can't keep a library online that people could access? PDFs that would be there?

Dr. Hann: We'd have to look at issues of copyright, for one thing, and how that's done. I don't have a problem and then everything would have to be considered in the public domain too, so if it's like a pre-manuscript obviously that wouldn't be appropriate for something like this. If it's already in PubMed that's easy because then we'd have the PubMed citation and then people can go to it. So there's some mechanical things. I personally don't have a problem with this. I think that's important for - this would be, I would see something to take back to the full committee to get their buy-

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in because it'll just be another piece of information.

Ms. Redwood: And if it was just one page with several links, this just came out, this just came out, and you could click the link and then go to PubMed and read the abstract or the paper, and it'd be a way for the committee to sort of be - because I know several of the other agencies aren't directly involved with autism, so it would be a way for them to also sort of stay current and be updated.

Dr. Hann: No, that's fine. I think though that I'd like to make it clear that this would be nominations coming from the committee.

Dr. Landis: So, I have -- so being a peer-reviewed published paper is no guarantee of truth. I mean, I hate as a scientist to say that, but there are different levels of rigor with which different journals review science. There are

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some journals, and I have even published in them, where if it's in the right format and there are no typographical errors it gets -- I have published in them and it but it was great data. They were great data. So I'm a little concerned about this committee giving an imprimatur, a stamp of approval just because something's published. And replication is -- so maybe I'm being unnecessarily --

Dr. Insel: I see your point, Story. I sort of see it more from Lyn's perspective I think. It seems to me that this is -- the IACC has the charge of creating the plan for science. And you want the people on that committee to know what's out there. And especially at this point if we're talking about what the updates would be, you want to make sure that they're hearing about whatever is happening, and maybe it's not even in autism. You know, maybe it's happening in some different field,

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but it could be tremendously helpful for autism. It just seems like both through the literature to the extent that we can make sure people stay abreast, but also even using the meetings to help educate the committee about where the research is going or where it could go would be really helpful. I don't think we've used the meetings that way up until this point, and we could. We could have people who come in and really serve this educational function, because you after all are going to turn to the members of the committee to make decisions about where we want the science to go. We want to make sure they know what's possible.

Ms. Singer: The previous IACC to this one used to have those science updates in the afternoon session. That was very helpful. It was very interesting.

Dr. Insel: Well, we could do that. We could do that again. And there are definitely some areas that did not really

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show up to any great extent in the strategic plan because they weren't ready six months ago, but they're emerging as being really important now, particularly around gene environment interactions and epigenetics and you know, I just came from a meeting where people are doing whole genomic epigenomics in the brain and that's pretty extraordinary stuff that's happening, not quite published but it looks like those will be very instructive tools for this field. And one would hope that maybe they won't be in the 2009 or -10 version, but the 2011 version anyway would be important for them. So, if this is one of the things that the subcommittee wants to recommend we can take this to the IACC and suggest that we use IACC meetings partly to inform the updating process by bringing scientists to talk about the most exciting work.

Ms. Blackwell: And I think it's more than scientists. I think it's also

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people who are looking at services, and supports, and what benefits people with autism most right now. So there's even a broader perspective that we could take in this respect.

Ms. Singer: I think Ellen, we can use the model that you've used in your services and support subcommittee where you brought some really good speakers to the full IACC to talk about services. I think if this subcommittee could replicate that model and really focus on science and bringing the scientists I think we would have a really good mix of presenters at the full IACC meeting.

Dr. Insel: To the last meeting where you brought the person who could talk about the state Medicaid situation was extremely helpful. In 35 minutes, 40 minutes, the two of you covered that whole landscape in a way that was really useful. I think that would be a great model for the

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IACC.

Dr. Landis: One nice thing about public presentations is it's possible -- I mean, at the meeting it's possible to ask questions and get input from around the table, and it makes it more personal and probably more effective than simply having a bulletin board. But I can understand the interest in a bulletin board.

Dr. Insel: So that would maybe be helpful for figuring out what's going on in autism. I'm still looking for how we find out what's not yet going on in autism that needs to, in autism research. Is there anything else we should be thinking about? This goes back to the original question of what kind of information is needed to update the plan. Anything else we should be thinking of?

Ms. Redwood: Tom, there's also quite a bit in the media. I know I just got an -- I did like the Google searches for

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autism and all the different things, and they pop in from the media and there was one that I think was actually in the New York Times today -- I didn't get to read it -- about Somalia. And I mentioned that at one of the last meetings and no one had heard about these, you know, this possibility of either a cluster or an epidemic of autism. So maybe even sort of surveying the media. When something interesting like that comes out I think it should be on our radar screen. But as I was saying, there's not really a mechanism in place for me as a member of IACC to send that out to the whole group. I think I tried to do that before and got in trouble with FACA or something, so that's what I'm asking is how can that stuff get to the entire committee. And you know, maybe even looking at not narrowly defining just things that are published in peer-reviewed journals, but there might be some opportunities for following up on things that come out of the

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media as well.

Dr. Insel: So that would be a different function altogether which is to use the -- I guess in this case it would be the office to keep the committee updated with anything that's emerging, that you think would be important to see.

Ms. Blackwell: I just have one other comment on the reconvening of an expert work group perhaps around the questions. I sort of disagree with Lyn respectfully. I think we should always be considering who the experts are, because I know there are folks that I would want to include now that maybe I hadn't thought of before. So I guess in terms of having the same people come as we had before, I'd like to just cast out that we should always be thinking of who we should include. And also that, you know, being mindful of the committee's resources. Maybe there is a way that we could convene such a meeting electronically instead of, you know,

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it was quite an endeavor to bring all those folks in. So I think we should always be cognizant that we should be trying to find ways to do this more easily so we can include everyone.

Ms. Redwood: Ellen, great point, and, no -- thank you.

Dr. Insel: How often do you think we should do this? You had mentioned September, Alison. Were you thinking of September of every year, or every other year, or once a year? What's the picture?

Ms. Singer: I think at least every year. I mean, the law requires every year, so I think we should do it at least once a year. You know, to Ellen's point though, I was looking at this sheet in here that has other meetings to see if we could somehow piggyback and save some of the committee's money by having our meeting as an offshoot of another meeting. So, there's the May IMFAR meeting where most of the

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scientists are gathered anyway.

Dr. Insel: Let's move the slides to the penultimate slide. There.

Ms. Singer: Their travel might be paid by their university, so maybe we could take advantage of that. I don't know how many of the scientists attend the ASA meeting. What is SFN and AACAP?

Dr. Insel: Society for Neuroscience which is in mid-October and the American Academy of Child and Adolescent Psychiatry which is soon thereafter. For the purposes of what's going on here I would think Society for Neuroscience is probably the best match at least for the first -- maybe not number 1, but 2 and 3 and maybe 4 as well.

Ms. Singer: And the timing on that one is good. I mean, that's the right time of the year.

Dr. Hann: Well, I mean, since you're looking at that slide, if the goal is

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to have an update by January I'm not certain that holding meetings that late will permit an update by January.

Ms. Redwood: Could we tag it onto IMFAR? I mean, IMFAR is a meeting specific for autism whereas the other meetings are not, and so I think we would be more likely to capture the people who have the cutting edge science, so.

Ms. Singer: I just think that's early this year. I mean, considering we just released the plan and we aren't funding anything under the plan, to try to do the update in May I think is just too soon. So normally I would say absolutely IMFAR, everybody will be at IMFAR, everybody's travel will have been paid. I just, I'm reluctant to wait till May of 2010, but I think May of 2009 may be too early. What do other people think?

Dr. Landis: So we may actually already be funding things relevant to the

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plan, it just wouldn't be new things. And I know, and maybe this was discussed before I got here, and I'm sorry I was late. It was a stem cell meeting. But there is going to be an effort to look at what NIH is funding, already funding with respect to the six questions, right?

Dr. Insel: Right. So the first part we talked about was the portfolio analysis, and we'd have to -- and we got some really good advice about what people want and they want to make sure it's not just NIH, but it's more comprehensive. So that piece we could do, that will probably take place over the next few months. We'll have that done I think by June, at least for 2008. We won't be able to do 2009 portfolio analysis until next spring, or February, March. So if we were to meet, and I'm just trying to think of what we would accomplish this year with a meeting either in May or in September because the -- we won't be able to look at anything

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we're currently funding because it will have just been funded, so we won't have any outcomes. We could review what was in -- what was funded before and we could look at what's coming from there, or we could use the meeting to try to pull in new ideas and see whether, you know, the six questions and you brought some experts together in the way that people are talking about, would you get some ideas that were not in the original plan.

Dr. Trevathan: I would just suggest that it's not a bad thing to look at what's funded before the current plan that addresses the six questions. I mean, that could be informative. I guess I would -- just wanted to make a case for the Society for Neuroscience. I mean, I think that some of the type of work that you are alluding to, Tom, you know that's not necessarily in the field of autism, but could definitely impact autism in thinking about what's coming down the road. If we connected with that meeting

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it's crosscutting enough and a lot of the cutting edge neuroscience is there. It seems like a good place to sort of capture a lot of the people we're interested in hearing from potentially. I know the timing isn't great for the plan, but we're updating this plan every year, and I can't think of a better time to get all those folks together. I think most neurologists don't go to the psychiatry meeting, most psychiatrists don't go to the neurology meetings. You know, so, but the Society for Neuroscience is an option to try to get a lot of different groups together at one time.

Ms. Redwood: Tom, we saw this just as mainly capturing new and emerging ideas. I don't see this as being related to the entire plan whatsoever. And do you attend the Society for Neuroscience's meeting?

Dr. Insel: I've never missed. Yes, that's the one meeting I go to every

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year.

Ms. Redwood: Could you update us?

I mean, I'm just wondering whether or not you could by attending -- Ed, do you attend?

Dr. Trevathan: Not every time, but I do. It's -- I mean, Tom can talk about. It's a huge meeting. To have one person summarize it would be a bit of a chore.

Ms. Redwood: But just the things that were emerging that might could cross where we could, you know, build on another area.

Dr. Trevathan: I was thinking in terms of thinking from a financial and budgetary point of view. It is a place where there's so many people doing science that relate to the developing brain and developing neuroscience that you sort of have a captive audience if you want to try to bring in some experts.

Dr. Insel: Yes, I think what may

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be hanging us up is that we're talking about two quite different things. There's a monitoring function that we're talking about which is important and which is going to be very different, I think, than the updating function. The monitoring I'm not sure how much there will be to do in 2009 because we're just getting going. Updating, you know, that's where you want to get the new ideas and new science in, and it may be that meetings are one way to do it, publications are another, and maybe holding a workshop is another way just to hear about the work that no one has even yet presented or is underway.

And it's -- what we may want to think about.

The IMFAR is probably the single best concentration of autism research, but as you pointed out, that's not until May of next year that it will really be useful. One option would be for us this year to hold a different, maybe a workshop that would look more specifically at going across the six

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questions and finding out what's missing. We would have to do that before -- really before October to be usable for the IACC because it's going to have to be -- we'll have to present updates to them in October so they can then be voted on in January so that we can stay on the schedule. So we don't have a lot of time here. And whether it's even reasonable to do updates for scientific reasons or not, what do you think? Should we give this thing a year to cook before we begin to go back to it and change it, or do you think -- and in the meantime we can look at where the investments are being made and ensure that we're monitoring it closely. What's your sense?

Ms. Redwood: There were some things though Tom in the plan that we specifically said we're not going to do this this time, this is going to be for next year. So I think we need to have a way to go back and make sure that we capture those, and I

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think we need to go back through this committee, the plan, and each of those six questions very critically and make sure, you know, that's the way we want it and maybe even present back a second draft to this committee and then to the IACC with how things might be worded differently along with the updates to the science.

One quick question about going to the Society for Neuroscience is that I would hate for us to focus just on the brain in autism. I think that would be a mistake. I think there's other organ systems that may very well, you know, play a role in autism too.

Ms. Blackwell: I would just add that -- I'm sorry -- I think our plan goes well beyond just the neuroscience. So if we focus on attaching ourselves to one meeting or two meetings we're just missing out on a plethora of other issues that we raised in the strategic plan. So I'm still sort of

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clinging to this idea of figuring out a way to have a convening of the experts. You know, people's budgets are really strapped right now, there's not a lot of travel money especially in the private sector, so I think if we try to think of some ways to include people that are cost effective that would be useful. I don't know Della, maybe that's what you've got to help us figure out.

Dr. Insel: IMFAR would accomplish that. Story had a comment.

Ms. Singer: Yes, that's the idea of piggybacking on the other meetings. IMFAR, for example, there are already over a thousand scientists who have registered for IMFAR and have paid. So we know that they'll be there. It may be that this year because it's a transitional year that we have our own workshop in September, but then start with IMFAR in 2010 and try to hold our meeting in conjunction with IMFAR to try to just save some of that money.

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Dr. Insel: Story?

Dr. Landis: So, there are stimulus dollars and I think there's a huge amount of excitement in a broad variety of communities, including the autism community for opportunities for new projects. And I don't want to get myself into trouble because I didn't hear everything you said, but you could imagine that responses to whatever opportunities might exist for autism research in response to stimulus money would reflect an extraordinary scan across the whole scientific spectrum, and from those requests, should there be such a thing, we would get a pretty good idea of what was at the cutting edge. So in a sense that may happen for us this May and June.

Dr. Insel: But how would we capture that? I mean, how would this group for instance know, and how would this group take that information and take it forward? That's what I'm not -- I'm not clear what the

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mechanics would be.

Dr. Landis: Well, I guess one question is what would be the role of program staff at NIH in extracting from whatever things came in. I mean, so I think there's a way to extract that information and those opportunities within the NIH. The question is how does that then get transformed into something that is useful and accessible to this committee, the broader committee.

Dr. Insel: Yes, so it's an interesting idea. We don't usually do this to think about you know, sort of getting the best scientific ideas based on how people, what they propose, assuming that that's - they're voting with their feet.

Dr. Landis: Right. They're voting with wow, this is an extraordinary opportunity. I mean, you've already seen that in the sense of the Pioneer Award applications. There was high enthusiasm for the use of induced pluripotent stem cells as

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a strategy. So every time there is a high-risk, high-innovation -- Eureka Awards is another example -- solicitation, then you're going to get the leading edge opportunity solicited. If they get funded it's no problem, you can go on the Pioneer website and see Dolmetsch's grant, but how you would actually capture the ones that don't get funded and the opportunities that they exist is more complicated because it's internal information for NIH. Just like you can't see the final progress reports unless you FOIA them, you can't see the grants that aren't funded. But I think that's going to be a very broad environmental scan.

Dr. Insel: So we've got the idea of bringing -

Dr. Landis: I don't know if that was clear.

Dr. Insel: So, one thing would be to bring scientists together for a workshop this year, probably not in connection with a

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meeting. A second possibility would be to use the grants coming in in response to stimulus money to get a scan of what people feel is the most exciting and greatest opportunity. We haven't talked at all about public input into this process and how we get those ideas for updating the plan.

Dr. Landis: An annual RFI?

Ms. Blackwell: Sounds good to me.

Dr. Landis: I just made that up. I didn't think about it.

Ms. Redwood: Maybe two. And you know, I participated in the town hall meeting out in California, and I think the more we can interface with the public the better off we'll be. So I would even propose at some point in time, maybe even before one of our IACC meetings or something to have a town hall meeting and to hear from the public and to hear from the parents as to what they think are the most important areas that we should be looking at.

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Ms. Blackwell: Since Lee's not here I'll speak for him, Lyn. He has a proposal that we're going to be discussing more at our services subcommittee meeting next week, but I think he might even have brought it up at our last full IACC meeting and certainly he brought it up the previous year, that he wants to throw forth an invitation at his annual meeting in Chicago for either the services subcommittee or the full IACC to have a town hall meeting.

So I'll let him, you know, discuss that at our next meeting and I'm sure he'll take it up with the subcommittee next week, but he was willing to provide some support and there will be at least a couple IACC members there I think. So that was his plan.

So you know, I'm not sure again, would that be a services subcommittee town hall meeting, or would it be an IACC town hall meeting. I mean, we'd have to take it up with the full committee.

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Ms. Redwood: I think that's nice to tie up the plan, and I know we tried to do that before with the last town hall meeting. I would only caution that we might -- with some of these conferences they're geared towards certain areas of, you know, certain parents attend certain conferences. Like there's a different type of parent that attends, say, the Autism One conference versus the ASA conference versus maybe the DAN! conferences. So we might want to spread out several.

Ms. Blackwell: I don't even think a person would have to attend, Lyn. I think there would be electronic opportunities for people to call in and comment. Exactly. So an individual or a family wouldn't have to be in Chicago, for example, to participate in the town hall meeting. We could even convene electronic town hall meetings.

Dr. Insel: But I'm hearing interest in town hall meetings of some sort.

We can figure out the best way to do it. But in terms of capturing public input, doing something like that.

Dr. Landis: Instead of or in addition to an RFI? The nice thing about an RFI is that people can sit in front of a computer and think and talk to their friends and talk to their physician. It doesn't require -- and introverts can deal easily with an RFI.

Dr. Hann: Can I just ask a question about the town hall, or the in-person. I won't even use town hall, but the in-person methodologies that you've just talked about. Are you thinking of that only with regard to public, or are you also thinking of that in terms of some sort of interaction of public with the scientists? Because I think that's really very valuable.

Ms. Redwood: I think both, Della. That's a good point. I know with the Autism Research Institute conferences there's a day

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that has like a science session and a parent session so you could sort of capture both. I don't know if ASA does that. I think Autism One does part of that where they have a combination of both there.

Dr. Insel: So one possibility since that ASA meeting is in mid to late July, that actually would be on the right schedule for trying to collect both public and scientific ideas.

Ms. Singer: I don't know how heavy on the science the ASA conference is. It does tend to focus more on supports and services.

Dr. Insel: No, my point was not that the scientists would be coming to ASA, but you might -- we might very well invite a group of people who we thought could help provide some insights on, let's say, Questions 1, 2 and 3, or some part of the plan that we wanted to get some help with in the short run. I'm throwing this out there,

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not because I think it'll work, but because I'm trying to figure out -- I'm looking at this timeline and trying to figure out how do we get information that will be ready to go to the IACC in October. And the only way to do that is if we are pulling things together over the summer.

Dr. Landis: That's six months. So when -- so anything that was funded in '08 and '09 from stimulus and any grants we would know about by the end of September.

Dr. Insel: Right. We wouldn't know in July, but we'll know probably end of -- well, certainly by September. Yes. So that makes all of this a little odd. That's why I think on the portfolio analysis side it's hopeless to do anything before then because that's the point at which you want to look at where the investments are going and how they align with the plan.

Dr. Landis: And you can have the before picture and know where we are now and

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how much of the plan was foreshadowed by what we're already doing. But we won't have anything substantive about the after picture.

Dr. Insel: So we will in a sense.

If you look at this map it has portfolio analysis getting completed in June, May or June, so that we can take that picture of what was funded in '08 to the IACC meeting and that will be the baseline. That'll be what we're calling pre-strategic plan. In a sense we would want to do that for the '09 budget maybe in January or February. We'll know more by the end of September, but we won't be able to pull it all together with RCDC and everything else until -- probably until January of '10.

Ms. Blackwell: Can I throw something out here -

Dr. Insel: Go ahead.

Ms. Blackwell: -- in terms of the timeline? We've been -- this map assumes that annual means January to January. Could

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annual mean `09 to `10? I mean, could we turn in -- I mean, is there anything in the rules that says we have to do this by January of 2010?

Dr. Insel: Yes.

Ms. Blackwell: Okay.

Dr. Insel: The requirement is an annual update which would mean January 26, 2010. That doesn't mean we have to -- I mean, if the group feels that the plan doesn't need to be updated, you could simply send in the same plan in January 2010. I can't imagine that there won't be something that we can't improve on. So that's -- I mean, I think the opportunity here is to figure out when in this calendar you want to build in those meetings to have people then be able to make recommendations about what's missing.

Ms. Blackwell: It takes so long to analyze the results of an RFI that I don't -- I mean, the plan is already out there. I

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almost think we should throw the RFI out there after the full group, you know, like throw it out to the full group at our next meeting. Because it's going to take awhile to write an RFI and it takes awhile to get the comments back, and then it takes awhile to analyze the comments.

Ms. Redwood: Could we not hold a webinar for the public to present the plan? Because it's not actually been formally presented to the public. I know it's on the website and it went to the Secretary, and then maybe you know, along with that webinar like Ellen was suggesting, allow for public comment at that time. And then tie that into after, you know, the webinar, that they have two or three weeks to actually submit in writing their comments the way that Story was suggesting for the people that are shy and may not speak up during a conference. But also, I want to get back to doing these other things that we talked about at the beginning

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of the meeting that aren't on here, like sort of a cost of disease analysis. I think that needs to be part of our update too.

Dr. Insel: So let's see if we can close this off and figure out what we've finally decided, because I think we need to go forward in -- to make a recommendation to the group in May about what we want. Let me try to summarize what I've heard you say, and we'll come back to what Lyn's asking about, which are the kind of larger scale issues like cost of disease. If we go back to -- let's go back three slides, can we do that? To the methods to update. There.

So what you're saying that we need is in terms of the types of information needed you want the portfolio analysis to be done, and that will be looking at '08. You want to come up with some way of looking at the impact of what's been funded, understanding that that probably is going to be a bigger factor in 2010 because we haven't

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yet funded anything directly from the plan, or we're just beginning to. And the third piece that I heard about was you're wanting to get information, because the first two have mostly to do with monitoring, you want to look at the actual updating function which has to do with getting new science, or science that is not completely represented in the way that you think it should be within the plan.

And we heard you say that that requires scientific input from potentially a workshop that we could hold that it would be good if, to the extent that we could that we make that a satellite of one of the scientific meetings, or any other meeting that we could do. You also want public input, and I heard RFI, town hall meeting, and this suggestion also about having sort of a webinar to present the strategic plan potentially as a way of launching the RFI so that we could explain that's in the plan at

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the same time that we talk to people about soliciting their comments about either what's there or what's missing.

Dr. Landis: Also collecting information from a broad spectrum of funders.

Dr. Insel: Right. That the portfolio analysis piece would not be just NIH or NIH and CDC, but it would be public and private funders to the extent that's possible.

Ms. Blackwell: Can we add one public funder to the list, and I apologize. It's not a big one, but the FDA might be a potential sister group that isn't on our list.

Dr. Insel: Good, thank you.

Ms. Redwood: Tom, I'm wondering too since you mentioned before about capturing input from the scientific community, if we might want to have like a webinar where we announce the plan to the public, but then a second one where we also

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share the plan with the science community, the people who are on the ground doing autism research now so they'll have an idea of what some of the areas of interest are and what some of our priorities are, and then solicit feedback from them and have a separate RFI for the science community and one for the public.

Dr. Insel: So we did that, we did a presentation last year at IMFAR just around the strategic plan and laid out -- it wasn't quite complete, but it was at the stage when we were looking for input, and we put out what was known, or what we had actually in quite a bit of detail, and it wasn't too far off from the final plan. And asked them for input, and asked them to also respond. I don't know how much that worked, but it's probably still feasible to do that as we go forward, to go back. I think people have seen the plan. I don't have any question about that because there's been a lot of

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chatter about what's there. And one of the things that we'll do, even if you look currently on the challenge grant website for the stimulus money, which is the first thing that's gone out, the language sort of basically says we're interested in funding research on autism that's aligned with the strategic plan, the IACC strategic plan, short-term objectives. Basically go see it and you'll know what we'll pay for. So, that probably does more than anything else we could do to make sure that people really do follow what's in the plan.

Dr. Landis: Where's the money?

Dr. Insel: That's right. But you know, what always happens, and Story, I'm sure you've seen this, is that people always assume that whatever they do is in the plan.

That somehow they read that as being oh, you're interested in what I'm doing. I always find that. So there is still a need for some conversation.

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Dr. Landis: But this challenges their ingenuity to make sure that they can warp what they're doing into the context of the plan. But you know, that just --

Ms. Singer: Is there going to be a strategic plan presentation again at INSAR this year?

Dr. Insel: Hasn't been invited and don't know that there's any interest. I don't know who's organizing.

Dr. Landis: I'm sorry, what's IMFAR? International?

Dr. Insel: International Meeting for Autism Research. And it's part of INSAR or something? Yes. Okay. Happy to do it. I mean, anybody from the IACC could do this.

Ms. Blackwell: I was just going to say, I'm not actually sure, Lyn, that we need to have a webinar to talk about the plan because the plan's there and anybody can read the plan. I just think what we might need to do is be really careful about how we word the

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RFI so that we can solicit, you know, the response that we want to get. That should be our focus. Decide what we want to know and ask those questions appropriately, and then get it out there as soon as possible, and perhaps we need to figure out like how much, you know, is there a 60-day comment period, or how long would this RFI be out there. But I'm not sure that we need to go through a webinar explaining the strategic plan because, as Tom said, it's here and we know people are reading it.

Dr. Hann: I just want to sort of poke at this a little bit because as I said, we've been giving this a lot of thought too about all of this. I mean, the idea of asking for public input is absolutely very important. I think the issue is the timing of it, and then obviously the modality by which that is done. The plan is out there and we've asked for comment on an earlier draft of the plan which, granted, was

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different, but not drastically different than what we've ended up with. So I'm wondering about the timing of asking for additional comment. Do we want to have comment now on the version that we have before us, or are we more interested in getting comment later on when there are suggested changes that might be made? So for example, if one goes through the portfolio analysis as Lyn was talking about earlier, and identifies gap areas based on the portfolio analysis so that therefore - - and I'm just throwing -- I'm not saying this is what will happen. I'm just giving you a scenario. So that you would like say, oh my goodness, there's a big gap on X. X really needs to have more work done on it. Maybe we need another objective on X in order that this work gets carried forward so therefore the plan would become different. Might that be at a point -- at that point be more useful, more instructive, getting public input at that point as opposed to earlier.

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Just throw it out there.

Ms. Blackwell: I guess there are people in the public that might also identify gaps. I mean, it goes both ways, right?

Dr. Hann: They did do that when -
- in the version that we showed them in August/September, because that version and they did identify issues and gaps which you all took into consideration in developing this version. So I'm just -- the timing of it --

Ms. Redwood: I'm wondering, Della, if we couldn't do both. Is that going to kill you?

Dr. Hann: Yes, there's a workload issue too.

Ms. Redwood: Okay. Because we don't have comment. We don't really have comment from what was finally approved. I mean, we did get comment before, but there were suggestions made that didn't get incorporated into the plan, so you know, I

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think that it's --

Dr. Hann: If the same suggestions are made again is that going to change? Because those were already given to the committee and there was decisions made. So, I'm just trying to figure out where we get the traction and where we move forward on all of this. Because if those same suggestions are made again, they were already made, the committee made a decision one way or another in terms of incorporation. So without new knowledge somehow coming into it all, I'm not sure what would happen with making those comments yet again.

Ms. Redwood: I see what you're saying, but I think some of those comments too need to be made again and need to be -- the committee needs to listen to them and reconsider them. I think every year we need to go forth with an open mind and not say just because we decided we weren't going to include this last year, we're not going to

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ever include it. So we've already heard that comment.

Dr. Hann: I'm just saying in terms of traction, do we want to somehow provide yet another version of this before we ask for the comments? They could still be the same comments.

Ms. Blackwell: So what would you propose the timing on that look like, Della, in terms of this timeline that we see before us here?

Dr. Hann: Well, what seems to be -- and this isn't easy, and I know not only from my staff but also speaking for the NIH staff involved, the portfolio analysis is going to be heroic this particular year given everything else that's going on at the NIH in terms of the stimulus funds and so forth.

Dr. Landis: And that it hasn't been done before putting it onto this plan.

Dr. Hann: That's right.

Dr. Landis: So not only --

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normally you'd just be looking at what's newly funded and adding it. Now you're going through five years of grants and contracts and intramural programs to do it. So I mean, maybe the thing to do is let this percolate for this year, get our act together, figure out the portfolio analysis, learn what's going to happen as a function of the stimulus moneys and the plan which we didn't have, and have a more modest goal for thinking about what we would be handing in in January. But I'm a gradualist and try to always have common sense, so I may not be as ambitious as we could possibly be.

Dr. Insel: You're sensitive to the workload. This is a huge amount of work because they'd be doing five -- we did some of this last March, so it's not completely novel, but it's still going to these six questions over five years of funding, so it would be complicated. Unless you said that you only wanted to look at what was funded in

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2008 as new grants. I don't think that's what people want. You want to know what's in the portfolio.

Dr. Landis: One of the issues that NINDS is grappling with with our stimulus money is to make sure that we're not planting any dead trees. You know, this Department of Public Works comes and they have a mission to plant trees on a street, Gail Collins editorial, someone called her and said they're planting dead trees. And there is a possibility with all this money that some of the trees. So we want to minimize that and I think in particular with autism we want to make sure that the stimulus dollars get invested in the best possible fashion. And to the extent that that is going to take time and thought.

Ms. Singer: Maybe if we schedule the scientific workshop for September the RFI could focus on generating data to inform the participants in the scientific workshop. I

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just, I get concerned with just continuing to put out an RFI that's not really tied to anything specific that's not -- where people don't feel like their comments are going to be actionable or acted on, that they're just -- because people say that to me all the time. They say well, you know, I sent in my comments and nothing happened. So I think if it can somehow be tied to a draft, or to inform an upcoming meeting I think it would be more successful. So I'm looking at the timeline here and September seems to be the only month that doesn't have a multitude of arrows pointing at it already, so maybe that's the time where we convene our workshop and maybe back at the end of July or August, maybe July we have the town hall meeting at the ASA and then we have the RFI at the end of July to inform the scientific workshop to take place in September.

Ms. Redwood: Tom, if you look at the CAA, I remember a sentence being in there

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saying that -- I'll have to pull it out, but basically you could go to the Secretary and say I need more staff, I need more financial support for this, and I'm sensitive to the concerns that there are a limited number of staff people you have right now working on this, and I'm wondering whether or not we might could outsource some of this. And as an example, the national vaccine program office or whatever, the meeting yesterday, they contracted with Keystone which does these types of things where they interface with the community and they set up a series of workshops, and I think they did an excellent job. Might we want to consider maybe outsourcing something like these RFIs process if it's so time-consuming to a company that specializes in something like that? Because I think, Alison, the point you made about people say, oh I submitted my comments and nothing became of that, they never heard back from us, did we consider

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them, did we look at them. That's why I think something that's an in-person meeting for those types of people to feel like their voices are being heard is important. Just putting out an RFI and saying submit your written comments, thank you very much, and you never hear anything back.

Ms. Blackwell: Lyn, I need to tell you that every single comment that was submitted on the services RFI was considered.

Every single word. I don't think that we treated the comments on the strategic plan RFI any differently. I mean, I'm sure Della can tell you that every comment was considered and analyzed.

Ms. Redwood: I'm not saying they weren't considered, but how did we communicate that back with the public?

Ms. Singer: I'm agreeing with you, Ellen. I think we did communicate it back with the public. What I'm commenting on is the suggestion to do an RFI now in

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response to having put out the strategic plan where it's not really -- that's not actionable in my opinion. I think the RFI that the services committee put out was absolutely actionable. I mean, we read every single comment, we categorized them and we put them into the plan. The same with the RFI responses to the research strategic plan.

You know, you went through painstakingly, numbered each one, and it was indexed and re-indexed, and voted on line by line, comma by comma. So I think people saw very specifically and clearly. Maybe the committee didn't agree, or didn't implement the suggestion, but every single suggestion was read and considered very extensively. So I'm not saying we should get rid of the RFI process. I'm just saying that I think the RFI process works better when it's tied to an actual event such as, Ellen, the one that you were describing for the services subcommittee.

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Dr. Insel: What about this idea that Lyn brings up, though, about having town hall meetings so that there's more interaction with the public. It's not just sending in a message. What's the sense of the group about that?

Dr. Trevathan: I really like that idea, personally. I mean, I think the town hall meetings are critically important. I think for us to put a face on the questions and the comments and then vice versa I think that's remarkably useful. I think unfortunately, in spite of technology, nothing really takes the place of the town hall meeting. So I know that having said that, you know, you can become absolutely overwhelmed with town hall meetings. You know, you can do too many and that becomes sort of a burden, but I think it would be useful. I know, for example, when Bruce Gellin came to speak to us, whenever that was, February, you know, he mentioned

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something about the town hall meetings that the NVAC had done, and I thought that was -- I don't know if --

Dr. Insel: That's the Keystone Group that held these things.

Dr. Trevathan: It's the same one, okay.

Dr. Insel: And so that's clearly an option, is that you could, as you're saying Lyn, you could outsource this. You could have a set of meetings. Is the sense -- I mean, I know CDC did something like this two or three years ago, and I know the NVAC is doing it. The question I have is whether -- I'm sure it's very useful for the people who can attend, but for the people who cannot attend, are they really left out?

Ms. Redwood: No. That's where they're allowed to submit written comments.

Ms. Blackwell: And also, for example, CMS is having a town hall meeting on dental services for children on April 6. And

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the meeting is at CMS, but we also have a webinar and a venue for the public who can't come to CMS to participate. So there are other ways, even if we do convene a face-to-face meeting, for people who can't be there to participate.

Ms. Redwood: And we also have a new Administration that's putting a focus on transparency in government. And you know, my point before was that the people on IACC know that we went through every single one of those comments and we considered them, but I don't know that the people, all those 500+ people who submitted them listened to our meeting to know that we did. So my point was more being able to communicate back with them what we did and how we came up with the plan because, you know, that was not that we hadn't done our job, Ellen, it was just that we hadn't communicated how we did our job back to the public. We never came out and said all these items were considered, and

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this is what we finally came up with, and this is our final product. That's what I was more trying to get at.

Dr. Insel: And remember, early on the IACC said we would do a series of town hall meetings in building the plan, and we did one, but we kind of ran out of time. Maybe it would make sense from what you're saying, Lyn, to put more energy into this than to an RFI, which as you say has built into it this skepticism about whether there really is transparency, whether there really is anyone listening at the other end. Whereas if you could do a series of meetings and have written input as well, maybe that would actually give us more of what we're looking for here, which is -- is some kind of interaction with a different -- a range of communities about where this plan is, what is in it and what may be missing from it. This kind of goes back to what you were saying about we never really did a kind of launch of

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this for the public. We put it out there, there was a press release, there was, you know, a little bit of chatter around it, but maybe it would make sense to do what the NVAC is doing. I think they're having three or four relatively small meetings, but they're well constructed, they're well organized and they have select topics to go after the issues related to vaccine safety. We could do that here. We could even do it by topics within the plan. I mean, there are a lot of ways we could handle this. But it would be nice to think about outsourcing this so we didn't have to do all the work ourselves.

Dr. Landis: So one -- I have two comments. The first is I've now been on the IACC long enough to know that there are different constituencies and communities who have a very different view of what the problems are, what the causes are, and what the strategies should be. For example, there is several groups who feel that autism is not

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a disease but an enrichment of the human condition, and I think if there are to be town hall meetings, there needs to be some mechanism by which one or another group doesn't monopolize the discussion. And I don't -- I mean, I guess if there are companies who do this for a living they know how to make good balance. And then the other question is I don't know if anyone ever responded to the people who sent in comments on the RFI. And I bring this up because we sent out a blast email about stimulus money and I had said write me if you have any thoughts, and I got 150 comments and it turns out that you know, 40 percent of them were basically the same thing. And I responded to all of those. Maybe not the best investment of my time, but it turned out to be pretty quick and I'm thinking that maybe in the future if we have an RFI that some sort of thank you very much, we took your comments -- you did do that. Fine.

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Dr. Hann: There was an immediate response to let them know that their comment had been received and that it was going to be taken into consideration by the committee.

Dr. Landis: But no --

Dr. Hann: Nothing personalized.

Dr. Landis: Nothing --

Dr. Hann: Nothing personalized. Dr.

Landis: And if you had 5,000 -- I mean, if you had tens of hundreds, that's obviously not feasible.

Ms. Singer: But do you have a list of the people who submitted comments and can we now just go back, and send them another email with the plan attached and say thank you for your -- your comments were considered, here's the final plan.

Dr. Hann: Sure.

Ms. Singer: That's something.

Ms. Redwood: One of the things that bothers me at the meetings is that people will get up and they'll make public

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comments and they'll ask a specific question, or they'll say something that's really thought-provoking, and we just go thank you very much, next person. And there's -- you know, that's just so impersonal. I think if we could somehow, you know, improve that process it would improve you public image.

Dr. Trevathan: I think it would be nice if there was some letter of appreciation, perhaps, or something like that that went to some of the people that make public comment. They spend their own money, they travel and I know when I've had the opportunity I thank them in the hall or say something, you know, on way out. But I think that is a great idea. And I have to apologize, I have my fourth meeting I have to run to. When you live in Atlanta but show up in D.C. periodically working for the government it tends to get booked. But thanks a lot. There are people at CDC listening so don't get off the line if you're

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from CDC. I want to hear from you tomorrow.

Dr. Landis: You could be working on stem cells.

Dr. Insel: We may -- thank you very much Ed for coming. We may be pretty close to getting what we needed from you today which was we need to take all of this to the May 4 meeting and to put in front of them this list of ideas that we want them to then give us a green light on. Is there anything else that we've left off? So once again, think about monitoring the plan, we talked about portfolio analysis, looking at impact, and the second piece is around updating the plan. Anything else that we should be putting in front of them?

Dr. Hann: I think we need a little bit more discussion on timing. I'll be honest, I'm a little fuzzy on timing issues. Yes, in terms of the timeline and what you all be recommending to the committee and when you're expecting to have information

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and so forth. Because I don't think the full committee will think through all of those ideas. I think that that needs to probably bubble up from the subcommittee. And also too if you're interested in having a portfolio analysis at the time point that we have there, we may need to put that out for a vote ahead of time electronically to the committee so that we can get started on it. It's a good process, it's very informative, but it's also very, very time-consuming on a number of people's parts, and the earlier we get going the better off we'll be.

Dr. Landis: I can't imagine we wouldn't want a portfolio analysis, right?

Dr. Hann: Again, the purpose of this committee was to come up with suggestions to take to the full committee.

Dr. Landis: So I think if you feel that the full committee needs to approve a portfolio analysis I would this afternoon draft something to send out to the full

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committee saying this committee recommends a portfolio analysis and that it needs to be done by the beginning of June and we would like -- and put in the context concurrence on this.

Dr. Insel: In fact, do we need the full committee to do this? At NIH, couldn't we simply say as an agency we want -
-

Dr. Landis: No, because we want all those other people's input and I think --

Dr. Insel: You mean for the other agencies?

Dr. Landis: Yes.

Dr. Insel: Yes, for that I know, but we could go ahead and -- right. So we could begin to pull that together well before May 4. We don't need to wait until May to ask people.

Dr. Landis: But I think you'd like to be able to send out an ask to all the other agencies, the IACC has unanimously or

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not unanimously endorsed a portfolio analysis that includes not only the federal agencies, but also private, and we would appreciate your -- as soon as we send you what we want.

Dr. Insel: So, do you want to do that electronically? Is that what you're recommending?

Dr. Landis: That's what I would like to do --

Dr. Hann: -- full committee electronically and not wait till the May 4 meeting to ask for their permission to do it.

Ms. Singer: I would include that to go to the private funders as well.

Dr. Insel: Because that's the part that we need them for. We don't need them for NIH. Is there any concern about that? We can do this right away. Okay, we'll go. So Della, you'll put something out for the group to vote on and we'll give them a couple of days to respond and then we can go forward. Okay. What else? That would be

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the first piece of the timing that you were concerned about. We can get that done. We'll set as a goal to get the portfolio analysis in hand well before the July meeting, sometime in June. Yes, okay. Any other ask before the May 4 meeting?

Ms. Redwood: Tom, I heard people seem like they were supportive of this idea of town hall meetings and also supportive of the idea of possibly outsourcing it to a group like Keystone. Could we get some more information about what something like that might cost so we could present that idea to the full IACC in May?

Dr. Insel: Let's do it. Let's give them some options of what we'd like to do and we hopefully -- you know, it would be great to be able to do two or three meetings before we get to the revision point.

Ms. Redwood: So I think we need that information first to really finish out this timeline. Because if Keystone says oh,

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no problem at all, we can do two or three meetings, we'll have a report, we'll have a representative come back to you, and you know, then we can plug that into this timeline. But right now we really can't do that.

Dr. Insel: Right. So, I mean, this was really a draft to give you something to discuss and the only thing that's fixed on here are the IACC meetings. And the bottom - - well yes, the due date, that's right, January 26, we know it doesn't change. But the -- and the meetings on the bottom which are not IACC meetings, we could or could not interact with them. And Alison, if you want to try to see whether we can get on the IMFAR agenda that would be great. I think that would be really helpful. It would also -- by then we would be able to give a lot more information about the stimulus money which I think many people at IMFAR might be interested in.

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Ms. Blackwell: Do we have the regular schedule for meeting as a strategic planning subcommittee?

Dr. Hann: That was part of the early -- right now, the discussion that we had at the open session of the IACC was that this was to plan the plan, if you will, to plan the process. It was unclear to me, anyway, the role of the subcommittee going forward in terms of actually working on and developing future versions of the plan.

Dr. Insel: So I think there were two things in the discussion. I agree with you Della that the committee wanted us to come back with a plan, but in the conversation at the committee there was clearly an interest in both the updates and monitoring function. Several people brought that up. And maybe it was unclear, but I think some of us assumed that this subcommittee would be doing that because it was too much for the committee as a whole to

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take on both of those functions. And we would report back whatever we do. We did not develop a schedule, so and actually that's the last item on the agenda, Ellen, is to figure out what we want to do for future meetings. Certainly we'll report back this conversation in May for May 4, but we should think about how we want to go forth from that point, and whether you want to meet on a regular basis between each IACC meeting, or how you want to do this, and whether you want to meet face to face, or by phone, or what would be most useful. Right now we don't have any data to work with so it'll be a little more interesting when we have something from the portfolio analysis at least from 2008 and you can begin to have something to really chew on. But without that, it's not -- I'm not sure that there's much we can do except come up with a plan.

Ms. Redwood: Maybe our next meeting should be after we have the portfolio

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analysis complete and we could do it by phone as a webinar versus an in-person meeting. I know that travel does get costly and so.

Dr. Insel: Are people okay with that? So we would plan to meet -- this would mean after June, sometime early summer probably, to be able to look at the -- probably it would be good to meet before July 29 anyway. So we could go through the portfolio analysis and be prepared to report that out for the July 29 meeting. Is that okay? Anything else we think we need to cover today? Story, you look like you're ready to go to stem cell.

Dr. Landis: I have stem cell.

Dr. Insel: Okay. Anything, Ellen, Lyn, Alison? What else?

Ms. Redwood: Okay, I'm going to make a plug again for, and I know this isn't something that you would do Tom, but maybe the Secretary to establish an autism advisory board as a sort of second layer to help

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review over the strategic plan and to solicit comment, and have that advisory board be a mix of researchers, scientists, and advocates.

Dr. Insel: So that will have to go to the Secretary. That's not going to be our call. But we will -- I think we will have a Secretary and we may even have a director of NIH, let's hope it's at least before the May 4 meeting. And remember, the director of NIH is supposed to be on the IACC. We haven't had anybody actually sitting in on the meetings, but it would be nice if she or he might actually be able to attend. That would be really interesting. Also, the other thing I heard from this meeting today if I got this right, Della, I hope this will be in the notes, is that you have an interest in using the IACC meetings, besides being nicer to the public comment people, but also to provide some scientific input and to have scientific presentations

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the way that was done at an earlier set of meetings. And we will look at -- even potentially we could do this starting in May where we could build in some piece. And then Lyn, your specific recommendation was that we use some of the May meeting to hear about the ACEs and the intramural program. And I was just looking at the schedule this morning. I think that's going to be easy. I mean, we have plenty of open time at the May meeting so I think that would be great if we can work that out.

Dr. Hann: So just -- not to drive home too fine a point. So, this group will meet -- so we'll have the portfolio analysis hopefully the beginning of June, that's the goal. This group will meet again before the July meeting of the IACC. You discussed potentially holding -- hopefully then at your meeting we will have the information on the Keystone conferences to take that into consideration with regard to potentially

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setting out a schedule for town hall meetings. Then there's also been some discussion today about potentially holding scientific workshops, or something like that potentially in September. Is that correct?

Dr. Insel: So that's a recommendation we'll make.

Dr. Hann: Okay. I'm just trying to confirm this so that I've got this right.

Dr. Insel: Right.

Dr. Hann: So the scientific workshops would be sometime in September. And then taking that information, whatever town halls have happened prior to that as well as the portfolio analysis. This group would then look at all of that information and make recommendations back to the committee about potential changes and updates. Again, I'm confirming. I'm not trying to put, you know. I just want to make sure I'm understanding you all.

Ms. Singer: It looks like there

would need to be, in between the scientific workshops in September and the full IACC meeting in October there would probably need to be a meeting of this subcommittee to review the material presented at the workshops and present that to the full IACC at the end of October.

Dr. Hann: Right.

Ms. Singer: So that's the only addition.

Dr. Insel: That could be done by - potentially could be done by phone.

Ms. Singer: Oh yes, yes. Phone is good.

Ms. Blackwell: I think that I'll just pass on a suggestion from the services subcommittee. I think that in the future we might also like to have space on the full agenda just to perhaps in addition to the scientific presentations that Alison mentioned, it'd be good to kind of keep services at the top too.

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Dr. Insel: When we looked at this -- this is a little bit off topic, but we were looking at this this morning for the May meeting and the recommendation came up to have David Mandell potentially come and present about what's going on in services research. I don't know if that would be helpful, or you had something else in mind. But we can talk about this offline and figure out how best to use the May meeting. But it is great to think about, now that we're not going to have to line by line through the plan at the May meeting, we can use this to get some new ideas and get some fresh perspectives.

Ms. Redwood: Could we also have somebody come in and talk about doing a cost of disease analysis? Ganz, or?

Dr. Insel: Yes. That would be -- there are two papers that we can go back to. Actually David does some of this, but.

Ms. Blackwell: Yes, I actually

think it's an area where the research is pretty insufficient at this point. So, I mean to me it's more of an item that should be on the strategic plan where we need more research going forward. Not so much, you know, we keep looking at what we have that may or may not be a hundred percent credible. So, that's where I would leave it.

Dr. Insel: But I wonder if it would make sense to have a presentation that kind of lays out -- so this has been done for cancer and heart disease. If we come up with what would be the need, what would you need to come up with a comprehensive picture. We just did this for serious mental illness. It took awhile, but it was actually a very useful exercise, to figure out all the different parts that you had to account for that nobody had ever done before. It is very, very complex.

Ms. Redwood: I know it's huge, but I think yes, no, we've got a huge

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problem.

Dr. Hann: Essentially it's a whole research endeavor in and of itself. It really is.

Dr. Insel: Yes, but all the more reason why you've got to do it. Right?

Dr. Hann: Right.

Dr. Insel: I mean, that's why you've really got to put a focus on it. Absolutely. Okay. Anything else before we adjourn? I want to thank the people who joined us on the phone and we're finishing early because the group has worked so well on this problem. And we will be bringing these ideas forward to the full committee on May 4. The meeting's adjourned. Thank you.

(Whereupon, the above-entitled matter went off the record at 2:19 p.m.)