

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

SUBCOMMITTEE FOR PLANNING THE ANNUAL
STRATEGIC PLAN UPDATING PROCESS
CONFERENCE CALL AND WEBINAR

WEDNESDAY, APRIL 19, 2010

The teleconference was held at
10:00 a.m., Thomas Insel, Chair, presiding.

PRESENT:

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

DELLA HANN, Ph.D., IACC Executive Secretary,
Office of Autism Research Coordination,
National Institute of Mental Health, and
Designated Federal Official

SUSAN DANIELS, Ph.D., Office of Autism
Research Coordination, National
Institute of Mental Health

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

LEE GROSSMAN, Autism Society

JENNIFER JOHNSON, Ed.D., Administration for
Children and Families

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

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

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

PRESENT (continued):

CATHY RICE, Ph.D., Centers for Disease Control
and Prevention

STEPHEN M. SHORE, Ed.D., Autism Spectrum
Consulting

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

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

TABLE OF CONTENTS

| | |
|---|----|
| Call to Order and Welcoming Remarks Dr. Thomas Insel | 4 |
| Approval of Minutes for October 15, 2009 Meeting..... | 5 |
| Discussion about Adding New Objectives to the Strategic Plan versus Measuring Progress Against Existing Objectives..... | 6 |
| Discussion of Methods for Measuring Progress Against Objectives | 12 |
| Discussion of Methods for Updating Question 3 and Question 4 of the Strategic Plan | 29 |
| Planning for April 30, 2010 Full IACC Committee Meeting | 60 |
| Adjournment | 64 |

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

PROCEEDINGS

10:00 a.m.

Dr. Insel: Thank you and welcome to this meeting of the Subcommittee for planning the annual Strategic Plan. We have on the call not only the members of the Subcommittee but this is also open to the public so this is available by webinar to all and we should take a moment to see who's with us on the phone so that members of the Subcommittee will know who is in attendance. I ask Susan if you could help us with the attendance.

(Introductions of subcommittee members and other participants).

Dr. Insel: We want to really use this time for two things - initially to make sure we approve the minutes from the last meeting which was in mid-October and to rather have free flowing discussions with you about how to take this forward for the 2011 update of the

Acclaro Research Solutions, Inc.

15316 Carroll Road
Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

Plan. So let's start with the approval of the October 15, 2009 minutes which you should have received a couple of weeks ago by email and the comments, questions, and revisions recommended. Hearing no comments I'm going to assume that the minutes are approved as sent and we'll move on to the main issue which is a set of questions which are here on the screen in front of you so you should be able to see the major issues. This may not take us the entire morning but we just really wanted to have the wisdom of this group about where we are going to take this update this coming year. We had a lot of discussions sort of late in the game about the 2010 version of this and a question about whether we wanted to use the same approach or change things going forward. If it's okay with all of you I will just start with each of these questions and get your input and then we'll move on to them in turn. The first one is the appropriate

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

balance of adding new objectives to the 2011 Strategic Plan versus measuring progress on the 2010 Plan or how much do we want to use the next update to change objectives and how much do we want to use it to measure our progress. I'll open this up for general discussion.

Dr. Koroshetz: I think what we want to do is make it clear from the old objectives if one comes off the list why it came off and to date the new objective. I think it's just confusing when the whole thing gets written again it's very hard to know what the timeline has been so in terms of balance I would guess that the old objectives are going to be solid by next year but a new objective should be defined in 2010 and not be rewritten into the old because then it makes it very hard to know what is actually happening from year to year.

Mr. Grossman: I'm curious to know what mechanism we have in place right now for

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

measuring the current progress on the Plan. I know that there will probably be updates at the various IACC meetings but are there measures that we have in place that show the actual dollars spent and the progress that has been made in those categories?

Dr. Insel: I think that may be the next slide. Lee - in response to your question there are a couple of options here - one is that we can use the portfolio analysis to look at how much money is being invested in different initiatives or different objectives, both from federal and private funders. The Summary of Advances was the other piece that had actually been put in place that would be a way of tracking progress on parts of the Plan and then it's also possible for us to use the meetings themselves or other meetings to bring together federal and private funders to find out what's actually been implemented and to use that as a way of making sure that there

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

aren't gaps in the initiatives going forward from what's in the Plan. If there are better ways to do this or if what you're really asking in a sense is we have a Strategic Plan but we don't have an implementation plan and is there a way to ensure that what's in the Plan is getting implemented.

Dr. Rice: What do people think about having some sort of time cycle where we say for two-year or three-year cycle the goal for any revision is really focused on evaluation and implementation and that if there are really emerging key priority objectives that need to be added that those are added but that's really held as pretty new in importance for the direction that needs to be taken versus the second or third or fourth or whatever year we decide that becomes a time to really go through the process like was done last year where we really evaluate the objectives in terms of do we need to rewrite

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

them and revise them to put a new cycle forward.

Dr. Koroshetz: I would hope that there will be advances made that will make new objectives as important as any of the old objectives. I think after all the work that you've done that it's going to be a result that triggers the next objective or some new finding that triggers the next objective. I like your idea of putting most of the emphasis on assessing what's been done on the old objectives and then potentially adding them as the science directs.

Dr. Johnson: I like that idea of giving the in depth review every three or four years because that makes sense from a Strategic Plan perspective in giving the Plan some time to utilize in the field essentially but I do think that at the same time we have to have a process for identifying as to whether an objective needs to be removed or not and, as

Acclaro Research Solutions, Inc.

15316 Carroll Road
Monkton, MD 21111
(410) 472-1447 www.acclaroresearch.com

Walter said, I think that would be tied to the current research and what we know and whether an objective is relevant or not. It seems like if we could strike a balance between the two that would probably work pretty well and it might be helpful to think of some criteria for evaluating our progress on the objectives both annually and the three to four year timeframe. I think having some clear indicators we're looking at to measure our progress - obviously the portfolio analysis is one way to do that but also with some of those objectives what's going to be the criteria to know whether that is right or not from a non-portfolio analysis perspective.

Ms. Redwood: I think as part of the Combating Autism Act we are required to do an update and review every year so I really think we need to do an in depth review and I'm wondering whether or not staff could actually look at each of the objectives and determine

Acclaro Research Solutions, Inc.

15316 Carroll Road
Monkton, MD 21111
(410) 472-1447 www.acclaroresearch.com

whether or not they're aware of any funding toward this objective over the last year since initiated and then give us some kind of report back and use that as one of the initial metrics for evaluating the Plan to see if there is any research in progress to date. I think that would be helpful as one of our first metrics for knowing whether or not we're actually accomplishing the objective we've set out to accomplish.

Dr. Insel: Other thoughts? So the message I'm hearing from the discussion is Lyn says it is in the statute that we do an annual update so that there's no question as to whether that's an option. The real option here is whether that update means changing objectives or it means mostly a review of progress on current objectives. So in 2010 we clearly chose the option A, we've added many objectives, we've removed a couple but we essentially almost doubled the number of

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

objectives that were in the Plan recognizing that in the original version - the 2009 version some things got left off the table that we really wanted to include. If the sense of this group is that what we have now is a pretty good list of the major targets then what I'm hearing from you is that what we want to do in 2011 with that update is to have A - reflect any new discoveries that may lead to the need for a new objective; B - eliminate any objectives that have been completed, and C - use this year mostly to look at progress made whether it's progress through funding or progress through actual research findings. Is that where we're at? It's quite different from where we were last year which was start from scratch and ask What Do We Know, What Do We Need all over again.

Dr. Johnson: I think in addition to looking at progress made we had talked about also looking at gaps and where the funding

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

gaps were.

Dr. Insel: Right, I think the same progress was both in investments and terms of findings so that would require again this extensive portfolio analysis which we've done each year but it would also mean that we would be pretty rigorous in the way that we link the portfolio analysis to each of the objectives of the Plan. We've done some of this but I think what I'm hearing from the group here is that this coming year we need to do that all over again and maybe with a little more granularity than what we've been able to do in the past. I'm just laying this out as a proposal so please clarify because what we'll want to do at the end is come up with a summary that we can take back to the full committee. As we just described it is what I'm hearing from you is something quite different from what we did last year. That takes us to Question number 2 and it sounds

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

like what we're mostly going to be about is Question number 1 and not adding new objectives but mostly looking at progress so then the question is how do we measure progress. This is the question that Lee already teed up for us. What I said in response to Lee a minute ago was that it was the portfolio analysis, the Summary of Advances, and then any additional meetings that need to happen whether it's at the IACC or independently to get a little more information about what's currently being done.

That would be a way of capturing the investments and identifying any gaps in both public and private funding relative to the Plan. The second piece of it by having the Summary of Advances might be one way of getting a sense of the actual scientific accomplishment and whether any of the goals have been completed or where the progress is on any of the goals. I do think it's

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

important in looking at these many objectives that we not just stop with the idea that the investments themselves are sufficient - they may be necessary but ultimately what you want is more than just spending money you want answers and so we have to have a way of capturing that as we look at the progress. Thoughts from the group as to how best to do this and is there anything more that we should be considering?

Dr. Rice: A question on the Summary of Advances - for next year would we use the 2009 Summary of Advances for our work as we evaluate this Plan this year?

Dr. Insel: Let's think about that for a second. I may need help from the crew here. The Summary of Advances is always the year before so we take publications from 2010 for this year but that means we won't be able to do that in total until next year in February so that's not going to work very well for

Acclaro Research Solutions, Inc.

15316 Carroll Road
Monkton, MD 21111
(410) 472-1447 www.acclaroresearch.com

doing an update that's due in January of 2010.

Any thoughts about how to do this in a better way and in a more timely way?

Dr. Koroshetz: I was thinking to be most relevant to the Plan is to break the Plan down into groups and each section have this is what the advances have been, this is what the funding has been in this area so that it would be much different than what we're doing now. I don't have the Plan in front of me but that seems like a possible mechanism so do you think we could do something like that?

Dr. Insel: I think we can do anything that the group wants. Let's find out how other people see this and I should add that the portfolio analysis, which is a piece of this too, we have to think about the timing of that. Ideally you want all of this information by October-November so that you could alter the Plan and have anything that you want to put in the update ready to go for

Acclaro Research Solutions, Inc.

15316 Carroll Road
Monkton, MD 21111
(410) 472-1447 www.acclaroresearch.com

a final committee vote in January. Our target every year is the end of January for the update and that's the one thing that we can't move - that's non-negotiable. So if we're talking about making the progress of the update both from the portfolio analysis and the Summary of Advances then we have to find a way to move this to somewhere in early fall. We can divide this up anyway the group wants to so let me see what other people are thinking about in getting this done.

Dr. Johnson: Back to the Summary of Advances - what if we sort of made our work at the end of the year a little bit easier and kind of a quarterly where members of the committee as new articles come out we recommend them to OARC and then there's some sort of process that helps us go through these many evaluations of the Summary of Advances to get to what's the latest in new research throughout the year.

Acclaro Research Solutions, Inc.

15316 Carroll Road
Monkton, MD 21111
(410) 472-1447 www.acclaroresearch.com

Ms. Redwood: Tom, I wanted to circle back to what you said a few minutes ago with regard to Question number 1. Were you saying that we would not be adding any new objectives because I also heard Walter say that we would evaluate this Plan and if an objective came off then there's new questions that arise based on research then there's also opportunity to add new objectives as necessary based on our analysis of what we know and what we need to know when we go through the Plan? So, were you saying that this year the decision would be not to add new objectives?

Dr. Insel: What I heard from the group was that in response to the question about what's the appropriate balance of adding new objectives to measuring progress is that people leaned heavily on measuring progress but they wanted to open the option that they could either remove or add objectives depending on progress made or discoveries made

Acclaro Research Solutions, Inc.

15316 Carroll Road
Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

that may not have been in the Plan at all and so something emerged in March-April of this year that suggested a fantastic opportunity for research then that would be considered a potential objective. People don't want to have another process where we've doubled objectives in 2011 beyond where they are in 2010 so that's why I'm saying it's quite different than what we were doing last year. I don't think we're talking about a rewriting of the Plan - it's more tweaking and spending more of our effort on the measuring progress side. What I'm hearing from the measuring progress side is the possibility that we do this in a slightly different timescale so maybe one way to do it is instead of every month if we were to break it up to have a July and December input of Summary of Advances - that is publications that could be considered for the update. This would be anything published between January 1, 2010 and June

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

30th or July 1, 2010 and there would be a second shot for the second half of the year where recommendations would come in at the beginning of January. I don't think we're talking about 100 or a thousand papers, it would be a small number of high-impact publications and would have relevance as to the Plan being changed or if an objective has been met. Is that going to be sufficient to give us the information that we want?

Dr. Koroshetz: It wouldn't just be in the papers, it would be where the funding is.

Dr. Insel: Della and Susan can tell me the timeframe for that. When is the portfolio analysis information collected?

Dr. Hann: For FY09 we should have the information for the portfolio analysis by this summer but it would be for the prior year.

Dr. Insel: The objectives that came out in January of 2010 there's no way of tying the portfolio analysis to those until next year.

Acclaro Research Solutions, Inc.

15316 Carroll Road
Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

Dr. Hann: The portfolio analysis is underway as we speak and it got delayed slightly because we did wait for the new Plan.

What's going out to the funders essentially are the objectives from the 2010 Plan and asking them to look at the grants that they are supporting and code according to the 2010 Plan.

Dr. Rice: Does it make sense to look at that data again in October so it will be instructive to the Plan revision?

Dr. Hann: Speaking for the NIH it won't be because the information from the NIH won't be available until January or February of 2011 for the funding that occurred for 2010.

Dr. Rice: I know this would create a significant amount of work but is there any way when you're also looking at funding in terms of having some type of metrics for determining the impact of it can you also find out whether or not the research has been

Acclaro Research Solutions, Inc.

15316 Carroll Road
Monkton, MD 21111
(410) 472-1447 www.acclaroresearch.com

completed and if there was a publication and what the findings were for that publication. That would really be a nice summary to have in terms of knowing what still needs to be pursued and what could possibly be removed in an objective.

Dr. Hann: Again, we can do that for an NIH portfolio. We are a little hamstrung for other agencies and the private funders - it would depend on their willingness to provide that kind of information. For the NIH portfolio we are able to because of the various reporting databases that we have available to know for a given grant to know what publications are emanating from a given grant. We also know if a given grant has been completed or if it's going to be going on as a continuation. We are able to discern that but; again, we don't have a luxury of a reporting database for the other funders and the private organizations. We would have to

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

depend on their willingness to provide us that kind of information.

Dr. Rice: I think it would really be helpful to have it. I know it would depend on the willingness. I know there are some publications coming out from the Department of Defense when it first started so hopefully we could gather up a fair amount to be able to determine what type of impact it has.

Dr. Hann: In prior discussions at the full committee meeting the committee had decided to not get that level of detail for the portfolio analysis. If the majority of the subcommittee wishes to change that I'll have to take it back to the full committee on the 30th for a vote.

Dr. Insel: Can we get a sense from other people who are interested in getting that information? We would have this from the federal grants - it would be a problem from the others but we can ask.

Acclaro Research Solutions, Inc.

15316 Carroll Road
Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

Dr. Johnson: It would be helpful to get as much information as possible but as you pointed out it could be potentially difficult to get it from other federal agencies and any private funders so we would have to take what we get and be happy with that or try something else.

Ms. Redwood: How difficult has it been in the past to get it from private funders?

Dr. Hann: It depends on the funder. We now have a working relationship with each of them so that does help. They don't necessarily quantify their grants according to our Plan so it does take them a while to do this for us. Frequently it takes anywhere from 3 to 5 weeks before we are actually able to get the data back from them and then we will have to reply back to them to make sure we clarify to make sure we understand what they're trying to communicate to us. Last year we had the information and when we

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

brought it back to the subcommittee then you all decided to also reclassify some it too. You coded it in different ways than what it originally had been coded. We give them the information, they code it to the best of their ability and then we have that information. We can ask them by all means - it's just something that's going to continue for another year and we can also ask if they are aware of any publications that emanated from those specific grants. I think those that have larger portfolios will obviously be more taxed than those that have small portfolios.

Dr. Insel: I'm trying to make sure I understand the concern. Is the issue that people worry that the investments being made aren't really supporting progress and people that are getting grants are not publishing or is it that we're not tracking this well or maybe we should define the problem a little better before we figure out the best solution.

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

Ms. Redwood: My concern was just that because something was funded it may not really give us the answers that we need and so that's why I thought it would be important to find out what the results were to see whether or not we need more research in that area or it that's adequate and it creates new questions.

I would think all of these concerns would be valid.

Dr. Insel: The other part of this is timing - if we funded something in 2009 or even 2010, let's say it's a clinical trial; it's likely that there won't be results for at least 2 or 3 years - or at least anything published because publications themselves can take 6 months after the paper is accepted if it is a clinical journal. I'm not sure how much we will get in 2010 that reflects on investments made in 2009. There may be some things but it would still be a year or two away from being able to harvest any of the

Acclaro Research Solutions, Inc.

15316 Carroll Road
Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

fruit of the investment. We may want to think about how to do this especially going forward.

The other piece to think about is we're looking at this from the other angle as well - we're asking about the most high impact publications so we have a chance to look at what the community has produced and then to track it back to where the investment came from to get that finding so we'll also have a picture from the Summary of Advances about where the progress is being made. What I'm trying to understand is whether we need to build anything else into this at this point besides the portfolio analysis and the Summary of Advances. Is there more information that we need to be collecting? We can, as Lyn is suggesting, we can ask for publications but anything else that would be informative about A - how the Plan is being implemented and B - where the progress is happening and where it's not happening.

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

Dr. Koroshetz: I may or may not know all the details but the portfolio analysis looked like it was primarily funding going to particular objectives. But you mentioned a call for clinical trials for a particular topic - is it possible then to break a portfolio down into a dollar because it could be a lot of money and how would we know that unless we broke down the grants somehow.

Dr. Insel: I'm pretty sure that's the way it comes out. It's pretty granular in terms of tying the funding into each piece of this. We did this last year at a slightly higher level. We can probably drill down a little more this year and we will have to because we have so many more objectives. There's always this challenge to make sure that you can link a particular grant to a particular objective. Often a grant will cover multiple objectives and figuring out how to do that is no easy task but in a sense what

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

we're about here is really looking for the gaps and what we want to know is are there whole areas of this Plan that just haven't gotten attention yet that we need to make sure the various agencies step up to and begin to implement. Anything else on this piece about how to measure progress? So what I'm hearing on this is that we use the current mechanisms that we've got but we step them up a little bit and we move them up in time so that we can use the information for the 2011 update rather than getting the information after the update.

Let's move on to Question number 3 which has to do with the different parts of the Plan so actually Questions 3 and 4 are not on the objectives but on the background for the objectives and so What Do We Know and Question 4 - What Do We Need. What approaches and activities can be used to help us with the update for both of these sections? Any thoughts about this from the subcommittee?

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

What do you want to do that we have been doing or haven't been doing as we go forward? If it's helpful to jog your memory about this - what we've done in the past is a whole range of things from workshops, public workshops, town hall meetings, RFI's, plans to have a suggestion box this year and we've also had other kinds of meetings just to get a sense both from the public and private groups about what they're investing in. We can do any or all of those, none of those, or we can do something different. It's really a question that comes to the subcommittee about what you want to recommend to the full committee about how we get information from the community for this next update.

Ms. Blackwell: I think the RFI approach always works well especially for people who can't participate so I think the suggestion box is a great idea too.

Mr. Grossman: When we issue the RFIs I

Acclaro Research Solutions, Inc.

15316 Carroll Road
Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

know there is a limited timeline for response.

Is that mandated or can we make it a much broader timeline? I know with some of the scheduling that we've had in the past it occurred times when people found it was much else going on and I think particularly on these two questions there's a lot that people want to add to it so I think if we could keep the RFI open a little longer - I think it's been a month that we've kept them open maybe - and give it a 2 or 2-1/2 month maybe we would probably get a better response.

Ms. Redwood: Also RFIs are limited to 500 characters so I think it makes it difficult to have a thoughtful response with those types of restraints.

Dr. Johnson: I didn't see the RFI last year to know how it was structured but was it structured to ask specific questions or was it more free form abroad in asking for information?

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

Dr. Hann: The RFI last year was structured around the 2009 Plan so I believe there was a series of 3 questions per area of the Plan and last year we had 6 chapters. For each section there was a chapter - essentially asking what other things were needed to be known, what else was needed, and what their ideas were with regard to scientific objectives. For each section, as Lyn just commented we limited the number of characters.

Part of it has to do with a web form which does need to provide a limit otherwise it becomes unruly and also for coding purposes. In terms of the timing of the RFI for the last few that we've done the primary driver is when the information is needed by the committee and then we work backwards. If the committee wants the information from the RFI available to it in October we would need to be able to close the RFI probably by the end of July in order to provide the time that's needed to do

Acclaro Research Solutions, Inc.

15316 Carroll Road
Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

the coding of the information. We could initiate the RFI relatively quickly - we have a format similar to last year. We have some of the nuts and bolts to push procedurally how to issue it. Theoretically we could probably get the RFI out sometime in May and then close it sometime in July.

Ms. Blackwell: I think that sounds good. That would give people several months to respond.

Dr. Johnson: How is the information used by the committee members?

Dr. Insel: I was about to ask you that question. Tell us if it was useful, what you did with it differently to make it more useful because we got extensive responses both in 2008 and 2009.

Dr. Johnson: My perspective is when you have a lot of qualitative information that you have to sift through on top of everything else I'm just wondering if it might be structured

Acclaro Research Solutions, Inc.

15316 Carroll Road
Monkton, MD 21111
(410) 472-1447 www.acclaroresearch.com

in a way that we might make it streamlining information and still allow for people to make their comments but is there a way we can have some questions quantitative in nature just to get a sense of how people are perceiving the Plan and how it's working. Last year I did view the information but there was so much of it that it's hard to take everything into consideration in addition to everything else that we were given.

Ms. Blackwell: Our group had two chapters at our scientific workshop and we did use the information from the public in terms of gap identification so I think stratifying it by chapter as we did before is really helpful.

Dr. Shore: The RFI could be targeted for what we really want to know which is what people think is important for lessons learned with regard to the objectives and also what the people think of the gaps. Seems to me

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

those are the two things we mainly like to hear from and to keep that front and center might be helpful.

Dr. Johnson: I would agree and also continuing the structure by having those questions embedded within each of those questions within the Plan so that it is easier to digest what someone is speaking about.

Ms. Redwood: I also don't think there was an opportunity to comment on the introduction to the Plan so if that could be added that could be helpful too.

Dr. Insel: I'm hearing that besides the introduction there's interest in keeping us organized around the 7 chapters - you want to break this down into questions so that people can respond to individual parts. Is that clear?

Ms. Blackwell: It also helps minimize extraneous information that isn't related directly to each chapter of the Plan.

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

Dr. Insel: Going back to Jennifer's comment, let me ask you what will make the RFI most useful to you as an IACC member? The idea is that we're trying to find out what we don't know and we want to hear from a broader audience that may actually be around the table or attending any of the meetings. If it feels like overload is there some way that we can make this more digestible or useful for you?

Dr. Johnson: Maybe we do some sort of quantitative aspect to it as well - some sort of rating of the Plan to kind of structure responses and have more of a quantitative response as well and opportunity for open comment which is organized by the utility of the Plan and gaps that Steven mentioned as well than by questions.

Dr. Insel: In the past it's been difficult to do that because even though it may look more quantitative there's no quality control for what comes in. The idea really is

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

to get a broad set of input. If you start asking people for numbers or ratings it's so difficult to be able to validate the numbers you have.

Ms. Redwood: The way we did it last year was useful and I don't know that it was overloading anyone.

Dr. Insel: For the group that I co-chaired with Steven we certainly dove into those responses. We didn't have a huge number but we had enough to give us some pretty good input. We found it helpful. I'm not sure that everybody that sent in comments found that their voice was heard but it actually was read. Going back to your issue of the limited length - I think some of that was to try to find a balance - to get lots of input but not overwhelming people and that's part of why there was a length limit put in here because the concern was that if you get really long passages in here that it will just flood the

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

system and that the unintended consequence of that is that the committee stops reading anything because there's so much for them to go through.

Dr. Hann: Last year there were 19 questions all total to cover each chapter and there were 500 characters per question.

Dr. Insel: Any other thoughts about how we get information? I haven't heard a lot of excitement about public workshops or town hall meetings or any other possible ways of getting input.

Ms. Blackwell: We did have a town hall meeting that again informed our thinking for Chapters 5 and 6 and we had a great analysis from OARC that we also used in consideration of updating those chapters.

Dr. Insel: Do we want to do town hall meetings this year? Is this something that people would feel would be useful exercise?

Dr. Johnson: One of the things we

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

exercised was that we didn't really have the expertise that we needed with regard to looking at the role of environment in autism.

I'm wondering if it might be helpful to have some type of town hall meeting around the areas that we're already identified as the areas of being gapped versus a large town hall meeting and if we could also somehow summarize the research presented at NFAR - I think we could use that information as well into the Plan.

Dr. Insel: In the past what we've done on gapped areas is we tried to use the scientific workshops to inform those rather than town hall meetings which are sometimes useful getting around what we need and not so much around what do we know. I did scientific workshops in both of these in the last two years and if we could do something this year prior to the update what's the sense from the group about the value of the workshops versus

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

the town hall meeting - we could do either, both, or neither depending on what kind of input the people want for the update in January. I remind you that what we're trying to do today is to come up with a set of options for the full committee so we'll take all of these recommendations to the full committee for their concurrence on this.

Dr. Koroshetz: I usually feel a little more sense of knowledge after a more in depth type of workshop on the particular area. Often times the depth of information at a town meeting seems to make me want to think that we need a scientific workshop in the area so I guess if we knew the areas that we thought were really the critical ones that the scientific workshops kind of get to the bottom of it and the town meetings are more trying to figure out which topics are the key ones. The scientific workshop seems to make more sense.

Dr. Rice: I would just the expectation

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

of the people is that it needs to be clearly framed and the scientific workshops of the past really became a true revision of the Plan. They could be helpful but I think that they should probably be more brief and focused on evaluation and critical gaps which are really essential to the Plan versus getting into a complete revision.

Ms. Blackwell: I agree - the scientific workshops are very helpful and it doesn't matter if we're structuring those in a way that we're getting the most useful information into the Plan so that we can meet the revisions that are necessary.

Dr. Insel: Do you want to stage this in a way that we use the RFI to identify the gap areas that need to then feed into a workshop or a town hall meeting? You wouldn't be able to do it for this year but you could do it for next year so then the idea would be to do an RFI in the fall as Lee had asked giving more

Acclaro Research Solutions, Inc.

15316 Carroll Road
Monkton, MD 21111
(410) 472-1447 www.acclaroresearch.com

time for the response and then you use that to generate a set of workshops in March or February of next year. That could really help to inform what happens in 2011 and 2012. From this conversation it sounds like there's a lot more interest in the RFI and we could do the workshops and town hall meeting. I'm not sure what the theme would be but we have some information about what a particular need or gap would be.

Dr. Rice: Could we not get the gap from the review staff is going to do when we get information from the funders and when we identify areas that whether or not they are receiving much attention or research or funding then we could have a workshop around that particular area?

Dr. Insel: I think that's a great idea from my perspective but just thinking about the timing we really won't have that much information until sometime in the fall. At

Acclaro Research Solutions, Inc.

15316 Carroll Road
Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

that point if you set up a workshop it's probably going to happen in February if you want to make sure that for the people you want to have put this on the calendars and you want to have at least 3 months to schedule and that's unlikely that we're going to get all that done by January.

Dr. Johnson: We have a deadline of July for getting in the funding. That would give us like we scheduled last year the end of September or early October. I think that would fit into our timeline of getting all of our edits done by November and then submitting it to the committee in December or January.

Dr. Insel: What's the sense of those here?

Dr. Hann: If we have the information by the July meeting for the committee to identify and have a discussion with regard to gaps then perhaps the earliest that we could theoretically get a workshop would be

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

September or October more likely. We're already moving into the time which the editing should begin with regard to the Plan. I'm just not certain that we're going to be able to accomplish it within the timeframe we have for the January update.

Dr. Koroshetz: As far as Lyn's idea - I don't know if it's legal or not with the autism meeting coming up whether or not we could come up with it so it wouldn't be based on the RFI this year.

Dr. Hann: That would be very useful. I think we have a number of committee members now who are also going to the NFAR meeting who could also be contributing to identifying gap areas and high profile issues that they think the Plan isn't covering and that they would like to see a workshop on. While I think OARC could be helpful I think the best set of ears would be the committee members who are attending the meeting.

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

Dr. Rice: I keep bringing this caution back because I also think in addition to gaps we also need to make sure that any RFI workshops or anything we put out are - a gap could be because there could be a good objective in the Plan but it's really an implementation problem and so I think we need to sort out are we talking about gaps in terms of new and exciting and important future directions that need to be addressed now or are we also talking about what's holding back and what is a gap in terms of implementation.

I don't want to get away from implementation so that we keep jumping to the new and exciting goal but the ones that were new and exciting in the past never got implemented. So just for us to keep that in mind and certainly the committee may not share that view but when we're talking about gaps also that is implementation focused as well.

Dr. Insel: Are there other thoughts

Acclaro Research Solutions, Inc.

15316 Carroll Road
Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

about this? The question on the table is how do we get information that we don't have especially about new opportunities. There are a number of possibilities - everything from distilling something that's heard from NFAR and bringing that forward quickly to using the portfolio analysis to identify gaps. Cathy: I think your point is a good one that we have to distinguish between gaps and implementation and new scientific opportunities that weren't on the table before and I think we're already hearing about some of those that have not been part of the Plan that would be considered as new areas for research in autism because they are productive areas of research and other areas of medicine. That would be one way to think about this. The other thing to point out is that we can also use the IACC meetings to hear about those kinds of opportunities that haven't been in the mix before and we can decide quickly at the IACC meeting with the

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

whole committee whether there's a gap area here that has emerged as a high potential area for science that we want to learn much more about through a workshop. That's why we brought up the epigenomics area at the last meeting and I think there are a couple of topics like this that are coming up at the next meeting. That's another way of doing this even without the portfolio analysis or the RFI or anything else. Lots of sources of information here and what I try to glean from the subcommittee is the sort of overall interest in having any kind of scientific workshop this year. What I'm hearing from the group is that it sounds like there is sufficient interest in having a workshop if we can identify an area that needs more information that would be kind of a step towards developing a new initiative in the Plan. It's always hard to do this by phone because you can't see heads nod but my sense

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

is the question becomes: how do we know that there is a real need for this? One thing that we could do since we're meeting on the 30th is that we could try to get a sense from the committee about how they would most like to identify topics and we could just provide the same conversation we're having now and tee up that these are our options and what do you as a committee want to do in terms of identifying a topic or having a scientific workshop. I hear the interest in being able to go deep in an area that we aren't currently supporting but what that area might be is something that I don't think any of us have quite figured out and how we identify the areas. As an option, how about if we take forward to the April 30th meeting the interest in having an additional RFI in 2010. I'm making sure that there is more time for people to respond to that and to do the RFI again by chapter and to pose specific questions which is what have we

Acclaro Research Solutions, Inc.

15316 Carroll Road
Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

learned and are there areas that we need to pay more attention to. We'll include the introduction as well as the formal chapters of the RFI and then to ask the full committee as well about their interest in having a scientific workshop and what they feel might be the best way to identify a topic or topics for that. This would be a little bit different than what we did last year. Last year we said let's have a series of scientific workshops around the whole Plan and I think that's where we ended up going down this path and said let's revise the Plan and rewrite it and the scientific workshops really became the original workshop. They took on their opportunity not to tweak it and rewrite it and double the number of objectives. In this case what I'm hearing from you is a focused approach looking at a specific topic that may be an emerging area. As an example we have yet to get a single objective around the

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

microbiome which is such an important area for the rest of medicine especially in developmental studies for Type 1 diabetes and other areas like this. That may be the kind of topic because it's tied into auto-immunity and it's the way that the brain develops and it may be a great area for us to think about for a scientific workshop and as a step toward developing a new initiative or new objective I should say. I think to identify that topic is going to take us figuring out how we're going to do that and I haven't heard here a clear pathway to that except in conversation with the full committee.

Dr. Koroshetz: The auto-immunity has been sticking in my head - the issue of auto-immunity development but it might be good to have a list before we go into discussion for people to think about whether we should go ahead or wait.

Dr. Insel: Are there other topics that

Acclaro Research Solutions, Inc.

15316 Carroll Road
Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

the subcommittee wants to bring forward? I can give you one other that's already in progress which is a meeting on drug development for autism which would be a combo of academia - people felt that this was a significant gap area so there's a joint effort between NIH and Autism Speaks to support a meeting around identifying essentially a drug discovery development for autism. That's something that is in the Plan but not in a way that is explicit. It's kind of in between some of the objectives. Are there other topics that you would want to bring to the full committee if we were going to give them a list of topics for potential workshops?

Ms. Redwood: I would think also a workshop on environmental factors would be helpful. I wish Cindy were on the call because it was said before that we really didn't have adequate representation when we did the workshops before regarding having

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

toxicologists there to comment. I would think that would be another area that would certainly qualify a workshop.

Dr. Rice: I agree with Lyn and specifically the measurement of environmental factors.

Mr. Grossman: I would suggest that we do one around services and support looking at the applied research education and service outcomes would be a great topic for a workshop. There's certainly a lot of information out there and this would help to bring it all together.

Ms. Blackwell: I concur with Lee and, Tom, when I was listening to you talking about the drug workshop I also think there should possibly be a component of how medications are presently used in the ASD population especially in terms of addressing challenging behaviors.

Dr. Shore: I think both of those are

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

really good ideas. I think we need more information on both.

Dr. Insel: Other topics? It sounds like we've got a list here. Anything else that you want to take to the full committee for their consideration? This is even without the RFI so we're doing pretty well here.

Dr. Hann: I just want to ask a clarification - there were two different timelines that were suggested for the RFI and I just want to try to get an understanding of where people are on this. One timeline is that we would issue an RFI in May with results being available in October. However, the discussion that followed that said that the usefulness of the real utility of an RFI for the committee is to identify new issues and then could potentially lead to workshops. If that's the case then it was also suggested that rather than doing it in May that we would issue the RFI in the fall and have it ready to

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

tee up. I just want to make sure that the timing of the RFI is the most useful to the committee.

Ms. Blackwell: Does there have to be one RFI? We haven't really received any comments from the public yet on what we published in January.

Dr. Hann: There's sort of two issues that flow with that. Again it's going back to the earlier conversation about how the information will be used. If the primary purpose of the information is to tee up additional workshops then the latter timeline seems more appropriate. If the RFI is being used to actually for making modifications in the current Plan for the update then the timeline essentially begins in May and we may want to have it end early in July knowing that there might be a series of workshops coming up. One of the difficulties that we ran into last year is that the RFI results and the

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

workshops all happened at the same time and I think it made it very difficult for the members of the committee and their respective subgroups to be able to actually use the information because it was way too much information all at one time.

Dr. Shore: I think this time the workshops would be more focused so I think that it would be easy to digest and incorporate in the purpose of the RFI primarily an understanding of what we've learned and what we think the gaps are for the Plan update. The workshops that come out of the RFI would probably be as Tom said for the year following.

Dr. Hann: If we issue an RFI in May and close it in the early part of July that information will come back to this working committee to determine how best to use it come September or October. In addition what I'm hearing is the enthusiasm for the focused

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

workshop that would also happen in September-October and having information from the focused workshop also feed into any potential revisions to the Plan for this year. That puts work primarily on the shoulders of the subcommittee in November and December.

Dr. Insel: It's really up to the subcommittee what you want to recommend but it seems to me when we started to talk about topics for workshops all of you had great ideas and those could easily be taken to the committee in two weeks and we could decide on an area that you want to dig deep on this year - let's say without the RFI feeding in and the RFI could be used essentially for quite a different purpose which is to identify other areas that then could become the topic of a later effort and maybe wouldn't be a workshop per se but would be part of the conversation about areas for revising or updating the Plan. The workshops themselves wouldn't have to be

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

contingent on what comes in through the RFI unless we don't think we have ideas enough but it sounds to me like we're there already just with the four or five things that people have recommended. We're going to have more than what we're able to do in this concurrent year.

Unless I hear other thoughts about this let me see if I can summarize where we're at for this call. We have one more question - what approaches or activities can be used to update the objectives for each chapter. Is it fair to say based on what we talked about so far that you want to use essentially the same approach - to take the information that's coming in from the portfolio analysis and the Summary of Advances from an RFI, hopefully from at least one scientific workshop, and to see if anything emerges from that which would lead to changing objectives, either reducing or increasing, or in some way tweaking an objective that's in the Plan currently.

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

Ms. Redwood: I have a question for the group that meets routinely about the intramural and extramural institutes that fund research and I think they are a wonderful resource and I was wondering if it would be feasible to ask them to look over the Plan for us and provide comments. I understand that group meets routinely - would it be feasible to get their input too and does anybody else think that would be of value?

Dr. Insel: We do get their input. They are kind of the worker bees on the implementation on this side of this because they're all in programs or at least at the NIH - they don't sit on the committee but they are the people who we talk to a lot and by a lot I mean virtually every day and so we know very much what they're up to and they know what we're up to and a lot of this implementation piece is about the handoff. I'm not sure what more could be done with that. If you'd like

Acclaro Research Solutions, Inc.

15316 Carroll Road
Monkton, MD 21111
(410) 472-1447 www.acclaroresearch.com

to hear from any of the people - it's called the NIH Coordinating Committee - we could have someone from that group come to one of the IACC meetings but I don't know that you would hear anymore from them that you hear from us but I guess we are basically representing those people at the NIH on what their program people are doing either in intramural or extramural.

Ms. Redwood: I just didn't know if they might have suggestions about gaps or I wanted to make sure that there was an opportunity to get their input on the Plan. If that's already happening then great. I just wanted to make sure that they were included in this process.

Dr. Insel: I think they are. Again, Della or Susan may have a better view from the Research Coordination Office but at least from where I sit that's sort of the first stop on any of these things so they are deeply

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

involved and they come to all of the meetings obviously but they are also deeply involved with questions about the implementation. In a sense when we do this gap analysis and there's some area that's not covered they are the first people to hear about it so we have to figure out how that's going to get fixed or patched. Let me see if I can summarize what I've heard from this conversation so far. The idea seems to be that what you want to take to the full committee on the 30th is a recommendation that this year when we do the next update on the Strategic Plan you want to really focus on measuring progress from last time (from the January version of the Plan), you also want to leave open the possibility of adding or taking away objectives, adding if there's some scientific new opportunity, taking away if some opportunity has been fulfilled and we no longer need to include it in the Plan. The way of doing that is I hear

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

from you is that you want to use the portfolio analysis and the Summary of Advances but to make those actionable we need to get them earlier so we'll plan to figure out a way to do this on a bi-annual instead of an annual basis - at least that's what we will propose to the committee. The portfolio analysis we'll get and then the other possibility is you want to put out an RFI which will again be by chapter, will focus on what's been learned getting input about any potential gap areas, and it will cover the introduction as well as all of the chapters and it will be out for a longer period. We'll have to post that sooner rather than later this year so we make certain that can inform whatever goes into the update.

It sounds like there is interest in having at least one scientific workshop but mostly this time on a very targeted area - what that area will be we'll talk about with the full committee and we'll come to them on April 30th

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

and come to them with a set of options but also leave it open for them to make recommendations as well about areas that they feel could represent kind of on ramps to a new objective but that we need much more scientific input about between now and January. Anything else that we should think about before April 30th that you want to make sure that we take to the full committee? Della or Susan - anything else that you want the subcommittee to help out on?

Dr. Hann: Just to clarify last year each member of the subcommittee identified a chapter that they sort of wanted to take under their wings in terms of helping to assimilate the situation and think through what the potential updates would be for that chapter. I just wanted to get a sense from the subcommittee if that is the thinking of how we will proceed because it would be essentially all of the information would be in around

Acclaro Research Solutions, Inc.

15316 Carroll Road
Monkton, MD 21111
(410) 472-1447 www.acclaroresearch.com

October-ish so that will give October to December essentially to summarize and propose additional changes to the Plan for the full committee. I'm just trying to make sure I understand the strategy so that once this information comes in that different members of the subcommittee will identify sections that they wish to work on and that they will do that - for the RFI responses, any workshop information that comes in, and the portfolio analysis and Summary of Advances.

Dr. Insel: I can see everybody's hands going up so I think we're good on this. Any other comments before we wrap up? If not, thanks for joining us by phone; we look forward to seeing all of you in a couple of weeks here in Washington. Remember we're going to be meeting this time at the Reagan building downtown not the NIH campus and we've got a very full agenda so I hope you're able to arrive early and stay for the whole day.

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com

It should be a really terrific meeting.

Ms. Redwood: It said on the agenda that the start time was 10:00 which is different. Can you confirm that this is the start?

Dr. Insel: That is right - we're going to start at 10:00 and even though we have a full agenda we wanted to have some people at the very beginning of the meeting who couldn't arrive until 10:00. Thanks everybody - we'll see you in a couple of weeks.

(The meeting adjourned at 12:00 p.m.)

Acclaro Research Solutions, Inc.

15316 Carroll Road

Monkton, MD 21111

(410) 472-1447 www.acclaroresearch.com