U. S. DEPARTMENT OF HEALTH & HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

SUBCOMMITTEE FOR PLANNING THE ANNUAL STRATEGIC PLAN UPDATING PROCESS

WEDNESDAY, SEPTEMBER 21, 2010

The meeting convened at 9:00 a.m., via teleconference, Thomas Insel, IACC Chair, presiding.

PARTICIPANTS:

- THOMAS INSEL, M.D., *IACC Chair*, National Institute of Mental Health (NIMH)
- DELLA HANN, Ph.D., Executive Secretary,
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- GERALDINE DAWSON, Ph.D., Autism Speaks
- LEE GROSSMAN, Autism Society
- JENNIFER JOHNSON, Ed.D. Administration for Children and Families (ACF), (representing Sharon Lewis)

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- WALTER KOROSHETZ, M.D., National Institute of Neurological Disorders and Stroke (NINDS)
- ARI NE'EMAN, Autistic Self-Advocacy Network (ASAN)
- LYN REDWOOD, R.N., M.S.N., Coalition for SafeMinds
- CATHERINE RICE, Ph.D., Centers for Disease Control and Prevention (CDC), (representing Coleen Boyle, Ph.D.)
- ALISON TEPPER SINGER, M.B.A., Autism Science Foundation (ASF)
- MARJORIE SOLOMON, Ph.D., M.B.A., University of California, Davis and M.I.N.D. Institute

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PROCEEDINGS

Dr. Insel: Good morning everyone. I hope you can hear fine. This is the meeting of the IACC (Interagency Autism Coordinating Committee) Subcommittee for Planning the Annual Strategic Plan Update Process. I don't even want to tell you what that acronym is, but it is a long one.

This is Tom Insel. We have a number of people around the table here at NIH (National Institutes of Health) from the Office of Autism Research Coordination (OARC). Let's first start with getting the roll call of who is on the phone. Maybe what I can do from our side because there is so many of you is just to read down the names of the members of this subcommittee. Please let me know, if you are present or not.

Ellen Blackwell (no response), Geri
Dawson(no response.)(Dog barking.) Someone's
dog is present, but I don't think that, Okay
(group laughter). Lee Grossman.

Mr. Grossman: I am here, yes, and

that's not my dog.

Dr. Insel: Okay, Jennifer Johnson (no response), Walter Koroshetz (no response),
Ari Ne'eman - Ari are you with us? Not yet.
Lyn Redwood (no response), Stephen Shore (no response).

Ms. Redwood: Lyn Redwood.

Dr. Insel: Lyn, welcome.

Ms. Redwood: Thank you.

Dr. Insel: Alison Singer.

Ms. Singer: I am here.

Dr. Insel: I am getting an echo, I don't know if you hear it on your end.

Ms. Singer: Yes.

Dr. Solomon: Yes.

Dr. Insel: We are going to see, if anything can be done about that. But let's just finish the roll call - Marjorie Solomon.

Dr. Soloman: I'm here.

Dr. Insel: Good. Welcome.

Dr. Soloman: Thank You.

Dr. Insel: and Cathy Rice.

Dr. Rice: Present for Coleen Boyle.

Dr. Insel: Alright. Thanks for joining, Cathy.

Mr. Grossman: Tom, this is Lee and Stephen Shore just texted me and he is teaching a class right now and won't be on the call.

Dr. Dawson: Hi Tom, this is Geri Dawson.

Dr. Insel: Terrific. Thanks for joining,
Geri. Anybody else joined since we did the
roster?

Dr. Insel: I know that Walter Koroshetz is going to be calling in just a moment. He had an off-site meeting, so I am not surprised. He is just a few minutes late.

But we are going to go ahead with the agenda at this point. Just to remind you that what we are about here today; is to really think about this process of updating this strategic plan. Some of you, who have been through this in previous years, know that a lot of this discussion is about what are the pieces of information that we need.

What should be the process? We have already had a bit of discussion about the scale and scope of this update. So let me start with that, which goes back to April 19th, when we had our previous meeting. We asked for you to review and recommend either revision or approval of the minutes from the previous subcommittee meeting. Now those minutes went out sometime yesterday.

Ms. Redwood: Tom, Approval.

Dr. Insel: Any other comments or revisions? (No response.) Can I ask for votes for approval in favor?

Multiple speakers: Yes, Yes.

Dr. Insel: Anyone opposed? (No response.) Okay, the minutes carry. Let's go on then to talk about this process for updating the plan. I thought maybe the best way to do that is just to kind of review what we have done so far for this 2011 update. We had keyed this up at the April 30th meeting of the whole IACC and just to remind you there was a slide presentation. We put a

bunch of questions kind of in front of you.

One is: 'What is the appropriate balance of adding new objectives versus measuring progress on current objectives?' discussion that followed, at least what the OARC notes show, is that the committee agreed that updates to the objectives of the plan should only be done if there are major new scientific breakthroughs. Something that was really quite unexpected last year and that would force an entirely new direction. committee for the most part, now that is the committee of the whole, not just this subcommittee, seems to want us to focus mostly on looking at the progress that we have had so far in implementing the plan. There was a discussion about the time course it takes just to make progress in science. Also, the discussion about the importance of continuing in the direction rather than shifting directions every year, just as people were getting their projects underway. So that was the first piece of this - was

the committee as a whole felt, I think pretty strongly, that they didn't want to rewrite the plan in 2011, but they did want us to dig in to what had been done to implement all of the work put on the table with them as a set of goals. Are there any comments or questions about that for the first point?

Mr. Ne'eman: Ari Ne'eman - I am joining. I am sorry I had trouble getting on the call.

Dr. Insel: OK. Welcome, Ari.

We are just going through the discussion that happened at the last IACC meeting, the full IACC meeting on April 30th to talk about this issue of updating the strategic plan.

The second question that we put in front of the full committee was: 'How should we measure progress on the plan from 2010 if this subcommittee is going to mostly be looking at progress rather than new initiatives.' Then they wanted, we needed, to have some metrics for that - is where we got into the whole conversation about using

the portfolio analysis to look at progress and to tie the portfolio analysis to the major objectives of the strategic plan. least, that was the way our notes reflected the discussion. It has been a while for those of you who were there, you might want to pass or revise to what I have just said. On the question about: 'What do we know?' Those sections in each of the plan, which is not in the objectives specifically but is in the sort of preamble of each chapter, the committee of the whole requested that we here at OARC prepare a mid-year report on the Summary of Advances. The problem of course, for the Summary of Advances was that it was coming so late that it wasn't really informing the plan in a way that it was useful. So what they asked for was something that would be available, I think we set a date of the end of August, or something like that could be shared. That has been done and you should have by now received that mid-year installment of the advances. Then a couple

more points here to sort of summarize what came out of that last meeting, there was apparently thoughtful and careful discussion about if we are going to be updating or evaluating or a little bit of both what would be the best sources of information. So, in addition, to the mid-year installment of summary of advances, the portfolio analysis was one way of looking really carefully at all those objectives which ones had been deployed. Where have we actually made investments? How were the investments doing? There was a chance to look at public comment that had come in, now some of that was public comment that we had gathered at the meeting themselves. All of which is written and which is distributed and is available to you. There is also public comment received in a response to an RFI (Request for Information), so an RFI has been submitted and is another way of bringing in fresh ideas. If there is some remarkable breakthrough that we are not currently funding or not currently involved

with, that would be one way of finding out about it. Then there is also a workshop that is going to be developed on services which may also key up some issues. Even though primarily, we are focused on the research side, there are sometimes research questions that are so relevant to how science goes into service that this could be helpful. So November 8th is the date of that workshop and that could also be a source of ideas for things that could go into the strategic plan.

That is a quick rundown of what came out of our last conversation about this at the IACC meeting. There may be other sources of information that you want to pull in at this point. Let me stop there and just see if there are comments or suggestions for anything else we want to consider. As we think about the next step towards updating the strategic plan.

Dr. Dawson: Tom, this is Geri. One possibility is, as you know, we had a meeting a couple of weeks ago at the NIEHS (National

Institute of Environmental Health Sciences). We brought in scientists from different fields who had success in looking at gene environment interactions and environmental exposures, particularly again as it might interact with genetic vulnerabilities. was a really interesting day. I guess one of things that I was really struck by was there was some technologies and informatics strategies - just the range of even statistical, you know, approaches that I think we would perhaps want to consider adding some of the things that came out of the workshop into the strategic plan. Ι know, I think that either Linda or Cindy will be doing a review of that at the IACC and developing a paper. So, I think, we could use that as a forum for looking at that. second thing is that we had a meeting that Alan Guttmacher [National Institute of Child Health and Human Development (NICHD)] attended in Toronto that was co-sponsored by many groups. It was on translation of

genetics into diagnostics - where do we stand?, what do we know? Out of that, also I think, came some potential research direction that might want to be. These are more like not necessarily new goals but new ways of reaching them, if that makes sense.

Dr. Insel: Could we bring that to the next IACC meeting?

Dr. Dawson: Sure.

Dr. Insel: So we can have reports. I know there will be one from NIEHS already, but perhaps we could ask you to give us the run down on the translation meeting?

Dr. Dawson: Right, I could certainly do it or we could ask someone just to come in for an hour, someone like Steve Scherer, who was actually at both meetings. But there are others that I think could come in and talk about what about we know about specific genetic subtypes. What are the recommendations? What is the research approach is going to be needed to translate what's going on in genetics from the point of

view of diagnostics. I would do it, but there are people that could do it better.

Dr. Insel: Okay.

Mr. Ne'eman: This is Ari - I would like to raise two additional possibilities. The one being I understand that there was recently a meeting around disparities in regards to ASD (Autism Spectrum Disorder). think it would be very interesting to incorporate some recognition of that in the strategic plan. Some of the priorities that came up there - given data that's already available but looks rather concerning around disparity access to diagnosis and services on the basis of income, race, gender, rural versus suburban, or urban. So, I think, it would be very interesting to incorporate something of that nature, but I believe Dr. Guttmacher's Institute (NICHD) played a role in that as well. Also, it is my understanding from the April 30th meeting, is that it is our intent to substantially add to the services section of the strategic plan

with the recognition that it has been under focus on in the past. With the Department's purpose for which will be convening a services workshop is to increase the representation of services issues in all of the IACC's work. So, I hope, we don't forget about that component as well.

Dr. Insel: A few things, Ari, the next IACC meeting will include a report out on the disparities workshop. Alice Kau will be doing that from the Child Health Institute (NICHD). Your comment reminds me that it might be useful to specifically ask her to comment on what is in the strategic plan to make sure that she draws a bridge between what is in the plan and what was discussed at the meeting, so if there is a gap, we have a chance to correct it.

On the question about the strategic plan and services correct me, I may be remembering this wrong, but I thought the major thrust of the discussion was the need to do more than just add on to the current strategic plan but

to really create an action agenda for services from the IACC it is in the Combating Autism Act (of 2006 S.843). The Act specifies that the strategic plan is for research but it makes it very clear that the IACC's agenda doesn't in any way limit our focus to research. So there is an interest, I know, within the Department, as well as from the various members of the IACC that we step up our activities with respect to services. I am just not sure that that is this plan. It seems to me that's really a call for something new and different and probably much more aggressive on the surface.

Mr. Ne'eman: I would agree. I think it is a call for something much more aggressive. I think what you are speaking, of some degree, a distinction between services policy and services research. I think I can say you've got someone who has been involved in the services subcommittee the direction the services subcommittee definitely wants to focus on services policy and systems change

recommendations. That is going to be the primary thing coming out of the workshop. Having said that, I think there still is recognition there to a very limited degree in the current strategic plan. It could be expanded in future strategic plans that services policy benefits from high quality services research, you know, as a result, my hope would be even as we see this parallel to more aggressive efforts to have the IACC fulfill its function on advising the Secretary on Federal activities related to ASD. In that the strategic plan process can also learn from that to fill gaps in the strategic plan around services that currently exist.

Dr. Insel: Ari, maybe one of the things we should make sure of what happens with all these pieces of information we are talking about like the portfolio analysis and Summary of Advances is that we do need to make sure that we are clear about what services research is being done. Who is doing it,

where it is being done, where the gaps are.

I'm not sure that any of us have seen that
entire list so this should be something again
by the 22nd of October which is our next
meeting. We have a chance to look at and
figure out whether there is a piece of this
we can define that could become part of the
update.

Anything else people would like to think about in terms of getting information to this group that would inform updating the plan. You mentioned just as the Autism Speaks meeting and the NIEHS meeting. There was a large Simon's Foundation meeting last week in Washington that went for two days bringing in some sixty or seventy different investigators that they are supporting. I think most of you know that the core of what they were doing was mostly around the big genetics efforts to find genetic signals in simplex families, that is, families with a single affected That is really only part what they now are supporting, so I think it will be

helpful to have this portfolio analysis. The people who came to this meeting with support from the Simon's Foundation had a broad range of different kinds of research. I think you will see that they are actually working hard on many parts of the strategic plan that are beyond just the genetics question; so that could be especially around biomarkers, so that may be another helpful addition that we will be able to get out with this portfolio analysis.

Are there any other thoughts about this in terms of what you would want to be able to fulfill our charge here to do the update?

Let me turn to Della (Hann) and Susan (Daniels) in terms of what the group can expect. We got a number of pieces of information that we want them to go through. How should they do that, when will they get them, what do we need back.

Dr. Hann: Right, this is Della. At the end of August I sent everyone the responses from the RFI - hopefully everyone has that,

if not I can resend it, but I know it did go out the end of August, as well as there were abstracts provided for the thirty-four articles that have been submitted for the mid-year installment of the summary of advances - so those two pieces of information hopefully you have. We are working on the portfolio analysis. It's always an interesting adventure working with all the funders in terms of having them code their information according to the plan. This year provided a little bubble in that the plan had changed so much it really did require extensive recoding on the part of the funders and that required extra time. We almost have that. I think we can get that out in the next day or two to you all. Then we also have the index of public comment that has been received by IACC which I will send along with the portfolio analysis that will be there for your information. I think and then we just talked about potentially the meeting summaries probably will not be available it

sounds like until the end of October.

Dr. Insel: It's the 22nd, I believe.

Dr. Hann: Yeah, until the 22nd so I think that's the pieces of information that we have at our disposal right now. The time line originally is, which certainly modifiable, what we really want to be able to...we always try to have a revised plan done at the January meeting so it can be submitted to the Secretary on an annual basis. So we have between now and the end of January essentially to be able to work on the updates. The updates in the past have been done by committee members. This is a plan of the committee, and by the committee. We in OARC try to facilitate that as much as we possibly can: a) by providing you with bits of information, but also, in terms of scheduling and so forth like that. Now last year was a different process. It was a more extensive review. What the committee elected to do was sort of a buddy system, if you will - that members of the subcommittee identified parts of the strategic plan that they wanted to work on. By parts, I mean chapters of the strategic plan they wanted to work on. Pairs worked on them together - so that would be one option that we could pursue again this year where pairs of committee members would review the pieces of information that I just talked about, as well as these meeting summaries that will come in to see how that might potentially affect a given chapter. Anything that the pairs essentially identify would then come back to the subcommittee for discussion then everything has to go to full committee for discussion and hopefully approval by the full committee in order for it to be considered a change to the plan. So that is sort of where we are as a potential process. We don't have to follow it. It is a potential process that could be used again this year. So, I leave it to you all to consider.

Dr. Insel: Della, what you are asking basically is do people want to buddy up there

are twelve people on the committee. We have got seven chapters plus the introduction so there are eight sections that people can work on if each person volunteers to do one or two, we could probably, unless everybody volunteers for the same section, we could probably get this covered. We could also assign them if you are more comfortable with that. What is the sense of the group? How do you want to get this done? Again, we are not rewriting it. We are talking about reviewing what's there, looking at all the comments that have come in, looking what's been done, and deciding whether there are any tweaks that would be helpful in 2011.

Dr. Rice: This is Cathy. For clarification - so last time the IACC members that sort of led a question that helped foster the scientific workshops that went along with it. So, we wouldn't do that process it sounds like. But how would the people who are in charge of a question get input from the rest of the committee? Would

that be part of the charge? Say if you are on question one, you would be getting input from all of the committee, or coming back to the committee with your suggestions?

Dr. Insel: Right. So, if you are in question one, you would take all the documents we are about to send you: portfolio analysis, mid-year installments, and public comments - all these things and look at them very carefully relevant to question one. whether there is anything out of that would recommend a change. You might draft that change and then bring it to the full committee for discussion. We could, also if you want, one of the other ways to do this, I don't think we are talking about a huge amount of change here. If group one could bring it back to this group and then this group could then decide what should go to the full committee.

Dr. Koroshetz: It's Walter. It seems to make sense the process. The only thing we might think about is developing some kind of

template that each of the groups could eventually use. So it has...there is some kind of continuity when the report comes out as opposed to people going off into all sorts of different directions.

Dr. Insel: Right, we would do that. That is a little bit the way we handled it last year so we would structure this and again each group is going to have a set number of inputs because there are really only three or four documents that will be working with. On the other hand somebody in the group went to the Simon's meeting or the Autism Speaks meeting and heard something that was just an extraordinary break through they think is going to really make a difference that the rest of the committee needs to know about, that could be worked in here as well. So, we want to leave that kind of flexibility to make sure that any breakthrough science can inform this process.

Dr. Koroshetz: Yeah, a point of

clarification - Do we have a list of what Simon's Foundation funds?

Dr. Insel: We do - That will be in the portfolio analysis.

Dr. Koroshetz: We will get that info?

Dr. Insel: Yeah,

Dr. Koroshetz: Okay.

Dr. Insel: Of course the flip side of this, if you are in group one or group two, whatever, it is actually group one might be a good one because one of the objectives was to develop a rapid screening tool for autism for use in the general population. If that has been completed, that will be a great thing for people to make note of as part of the update to allow the IACC to check off one objective as done. That could also be a way of doing an update. Those kinds of things could be very helpful. It is not just new stuff that we need to d, but stuff that is in the plan we don't need to keep doing it if it is already completed. There might not be a great many of those, we are thinking about

this. Also, we are two years in, so there ought to be some good evidence that the plan has changed what we do and we have actually completed some pieces of it.

Dr. Koroshetz: Right.

Dr. Dawson: Yeah. This is Geri, I do
think there will be several of the objectives
where they may not be completed but clearly
they are in progress and should be completed
in the next year or two. So I think that is
really important part to put into the plan
because then we can identify what is left
that hasn't really had the investment yet
even though it was identified as an
objective.

Dr. Insel: Right. Right.

Dr. Dawson: In regarding the assignment, one thing would be, if you sent us the list of, I guess we know the questions by now; we could each just send you two choices then you could sort it out. I think otherwise it would be hard on your end to figure out how to do it.

Dr. Hann: Geri, this is Della. I think it's best actually we do that on the phone call, today.

Dr. Dawson: Oh. Okay.

Dr. Hann: You have the assignments?

Dr. Dawson: You are talking about the six questions or how many are there now?

There are seven questions plus introduction.

Ms. Redwood: Tom, this is Lyn. I also think it would be important for all of the Planning Subcommittee members to have an opportunity to comment on the plan after the different team captains or whatever to make their recommendations, before it goes before the full committee for discussion.

Dr. Insel: Thank you. That's a great idea and actually I think that's an important point to make if you are volunteering to do chapter one, you are just volunteering on behalf of this subcommittee. We are going to need everybody's best ideas for each of the chapters and introduction. So this is really the task of the whole subcommittee to do this

update. We were just trying to figure out the way to divide up the work on this first pass and the second pass will be for each of you to share with the whole subcommittee before it goes before the full committee. Thank you for that clarification. Because we want to take this to the full committee on the 22nd of October which is the next meeting, we are hoping that we can have a another conversation with this whole subcommittee sometime in the next couple of weeks that we actually have a date we picked up as a possibility.

Let's first get, if we can get the volunteers for each of these sections, then we'll know who will do what. Again, I don't think this is a huge amount of work as you will see because it is divided up into eight chunks and there is only a limited amount of stuff that could be coming to you. If you can just pair off, take a look at this, and each of you can get this done fairly quickly. Then as Lyn says, she'll come back and

report out at the next meeting about the next subcommittee meeting. Things that are completed, things that are unaddressed, and things that need to be added; it essentially this is progress report in that sense.

Dr. Hann: Right, This is Della. We can provide certainly the information for each chapter in a word format; so it is something that you could go in and work with. As you will recall each chapter not the introduction, but each of the parts of the plan are divided into sections. In terms of what do we know, what do we need, and then some basic research kinds of questions and then the objectives. So the committee can essentially take each section, if I was assigned to question one, for example, I would go through each section based off the information that we will be sending you to determine are there any changes that need to be made to the what are we know section. That would be the first thing, are there any changes that need to be made to the what do

we need section, and the third thing are there any changes to the research questions and objectives there can also be a fourth section which we never had in the plan, but I think based on this morning's discussion is certainly sounds doable that we could have a fourth section in terms of the progress that has been made in reaching the objective and a paragraph could be written and added essentially to the plan. So that would be the task that is the two people who are assigned to go through their particular chapter and identify what kind of updates need to be made to the different sections within that chapter. Then again based upon what we just said, that information would come back to the planning committee at a meeting and that would be discussed with fellow members of the planning committee.

Dr.Dawson: Della, I really like your idea of adding that last section and that is actually how we have been updating the Autism Speaks strategic plan adding among other

things. Adding a section what was accomplished each year, but we could look at the last two years and say what was accomplished.

Dr. Hann: Right.

Dr. Dawson: It could include money going towards things, as well as, completed projects but it really gives you a sense of where the gaps are.

Dr. Hann: Right. You will see when we send out the portfolio analysis that there is a couple of sections of the portfolio analysis that I think may lend itself very nicely to that. We have information that we pulled together across the funders that indicates per objective the number of projects going on in that arena and the dollars essentially for 2009 that were devoted to that particular topic. So that does actually provides almost a tabular way of saying which of these objectives are gaining attention essentially by the research community and which are not. It doesn't

speak to the scientific progress that is being made but it does in terms of the funding process if you will.

Dr. Insel: It just is 2009 dollars?

Dr. Hann: It is 2009.

Dr. Insel: It won't have the 2010 picture.

Dr. Hann: No.

Dr. Dawson: Well I would be happy to do
Treatments and Interventions, if you wish. I
am also willing to take on other sections, if
you

need me.

Dr. Insel: Okay, Thanks. Why don't we just go down the list? So Geri, I think you are the first one because Ellen Blackwell:
Are you on the phone with us yet? Ellen
Blackwell, so we can assign Ellen. So, Geri we have you down for Chapter Four basically and we will need a volunteer to do the introduction section as well.

Dr. Insel: Lee.

Mr. Grossman: First of all let me tell

you that Stephen Shore e-mailed and he wanted to be considered for Which Treatment and Intervention Will Help? which is Chapter Four, I believe.

Dr. Insel: Yeah.

Mr. Grossman: Well, I can go with either Chapters Three, Four, or Five, whatever people feel - whatever the committee's pleasure is on that, I am open to any of those.

Dr. Soloman: This is Marjorie. I don't have my strategic plan in front of me, could we please take a brief minute to say what each of the chapters was?

Dr. Insel: Sure can. Della, you want to take us through that?

Dr. Hann: Sure, Marjorie, if you go to IACC website. Are you in front of a computer?

Dr. Soloman: Hold on a second.

Dr. Koroshetz: I am not actually.

Dr. Insel: Let me quickly do it. There

are seven and the introduction which talks about the broad needs the values of the committee and vision, there are seven chapters.

The first is: When should I be concerned?

The second is: How can I understand what is

happening?

The third is: What caused this to happen and can it be prevented?

The fourth is: Which treatments and interventions will help?

The fifth is: Where can I turn for services?

The sixth is: What does the future hold,

particularly for adults?

The seventh is: Infrastructure and surveillance needs and how will those be met?

Mr. Ne'eman: This is Ari, I would be interested in either four, five, or six.

Dr. Insel: Okay, let me just again go through Jennifer Johnson are you with us (no response) and Walter?

Dr. Koroshetz: Yeah, I am here.

Dr. Insel: Any of those?

Dr. Koroshetz: I think I could fit in the cause or when should I be concerned - I think either of those two so its three, two, or one, or something like that, one, two, or three.

Dr. Insel: Yea, this is getting stochastic here. We will see how it all works out. Lyn Redwood or Ari we have you down for four, five, or six. Is that right?

Mr. Ne'eman: Yeah. I said four, five or six.

Dr. Insel: Lyn Redwood

Ms. Redwood: Question number three or four.

Dr. Insel: got it.

Ms. Redwood: We have a lot of people for four, so question three.

Dr. Insel: Alright, and Alison.

Ms. Singer: Two and seven.

Dr. Insel: Okay. Marjorie.

Dr. Soloman: Two and six.

Dr. Insel: Okay and Cathy Rice.

Dr. Rice: Seven and anywhere else needed.

Dr. Insel: I think you might get one.

Dr. Rice: Okay.

Dr. Insel: Because that deals with some of the surveillance tools as well.

Dr. Rice: So I know that is primarily in seven.

Dr. Insel: Yeah, there is little bit in both. One has some diagnostic, yeah, the screening tools, so that would be great to have you look at that. Susan, how are we doing? Have we got everything covered?

Dr. Daniels: Let's walk through each chapter. Let's skip the introduction, 'when should I be concerned?' which has to do with diagnostics and screening tools, the two people who have sort of volunteered for that are Walter (Koroshetz) and Cathy (Rice).

Dr. Insel: Okay.

Dr.Daniels: Okay, then for the second chapter 'how do I understand what is happening?' tends to focus on the early brain

development the people who have volunteered include Alison (Singer), Marjorie (Solomon), and Walter (Koroshetz).

Dr. Insel: Okay.

Dr.Daniels: Okay.

Dr. Insel: 'What caused this to happen and can it be prevented?'

Dr.Daniels: We have Lee (Grossman)
Walter (Koroshetz) and Lyn (Redwood). Is that
okay with everyone?

Mr. Grossman: Yeah

Dr. Insel: Which treatments and interventions will help?

Dr. Daniels: We have a number of people who are interested in Chapter Four: Geri Dawson, Stephen Shore, Lee (Grossman), Ari (Ne'eman), and that's it, and oh, Lyn (Redwood) excuse me.

Dr. Insel: That sounds good if we have that much interest as long as somebody takes charge to make sure this gets done, that's great.

Dr. Insel: 'Where can I turn for

services?'

Dr.Daniels: Let's see Chapter Five is Lee (Grossman), and Ari (Ne'eman).

Dr. Insel: I would think that Ellen (Blackwell) would also be very interested in that chapter so we will volunteer Ellen.

Dr. Insel: `What does the future hold particularly for adults?' - Has anybody signed up for that?

Dr. Daniels: Yes, Ari (Ne'eman) and Marjorie (Solomon).

Dr. Insel: Let's ask Ellen (Blackwell)
to take a look at that as well and Lee
(Grossman) is that something you can take a
look at?

Mr. Grossman: Ah, yes.

Dr. Insel: 'What are the infrastructure and surveillance needs?'That is important - so that is Alison (Singer) and Cathy (Rice) have agreed to do that. Geri (Dawson) can I twist your arm on that?

Dr. Dawson: I am actually willing do any of them honestly.

Dr. Insel: Because I think there are some issues around bio-repositories. We need to make sure we have all the language right in there.

Dr. Dawson: So I would be happy to do seven.

Dr. Insel: We have several people for seven. We have Alison (Singer), Cathy (Rice), Geri (Dawson) and, anyone else who would be interested? Jump onboard.

Ms. Redwood: Tom this is Lyn, I would also be interested helping with the introduction and Question Two.

Dr. Insel: I don't know if anyone has offered to work on the introduction. No one has and you have just gotten the job. So, you are hired. I might help you with that since I have not signed up for anything. I can work with you on that and let's see if anyone else is interested in the introductory part as well.

Ms. Redwood: That would be great.

Ms. Singer: I would be happy to work on

the introduction as well.

Dr. Insel: Okay, thanks Alison. I think we are covered.

Dr. Daniels: Do you want to assign Jennifer Johnson maybe one?

Dr. Insel: Okay, let's put Jennifer

Johnson on number one. This is the

punishment for not showing up on the

conference call. Okay, so we have everybody

signed up for the buddy system.

Dr. Hann: There are multiple buddies.

Dr. Insel: Della, why don't you let them know how you want that to run and then what the plan will be feeding back?

Dr. Hann: So after today's meeting, I will send out to everyone a repeat of their assignments. Please double check it in case we made an error or if you have had second thoughts with regards to doing the assignment. Hopefully not.

Dr. Insel: No give backs.

Dr. Hann: Tom says no give backs with your assignments. Also, we will include Word

version of each chapter so you can have that and so you can mark it up a little bit more easily with track changes if you choose through Word. I will, also, probably do this in a stage manner in terms of e-mails, because I think it will be a fair amount just to hang on to one e-mail. We will be sending you the portfolio analysis. I will resend the information on the Summary of Advances. I will also resend the RFI. I will send to you the index of public comments. So those are the tools and materials, we have essentially at our disposal for you right now for you to begin your task of considering where things would change. I will also provide essentially a template, if you will, of questions for you to think about when you go through each section. It will be minimal, but it will provide a little structure to the kind of task you have before you in terms of identifying issues for each section. what I am seeing as the immediate next step to get all that back out to you and then as

Tom mentioned we did have a preliminary date identified for when the subcommittee could get together again and that would be October 6th in the morning from 9 to 12. We would like to convene and welcome anyone to come actually here to Washington and to participate live here at the table. I realize that might not be feasible for everyone, so obviously we will have the telephone lines available too. In the past, when the subcommittee, as well as the full committee has worked on the plan it is has been very useful to have people able to interact directly with each other and not through an electronic mode but that can always be accommodated. We will accommodate you. We will do the best of our abilities in terms of both live at the table as well as phoning in. The idea for the 6th would be for each person to have gone through their assignments essentially and come prepared to discuss the kinds of changes they would recommend the group to consider making to the plan.

extent you can provide us that material two days in advance of the meeting, we will actually provide those materials to other members, to have it available to other members, and have it available electronically for people to see during the discussion. I remind you that this whole process is done in a public venue. We are public today, the meeting on the 6th would be public as well, certainly, the full IACC meeting on the 22nd is public.

Dr. Dawson: Della, this is Geri. Are you going to assign a team leader so there is one person who sort of feels responsible? Or are you going to be running the calls and setting up and all that you know. I am just wondering if you are going to do that or just work as a herd.

Dr. Insel: Well, to make things easy when we send out the information again and we send out the list, we will have someone assigned a convener for each group. It is almost random.

Dr. Dawson: I don't think it matters who it is if one could do that, I think, it would be easier.

Dr. Hann: Right, I would encourage those if you have conference calls with the group which is fine that you include Susan and myself in those e-mails that set that up, again because of FACA [Federal Advisory Committee Act] rules more than two to three members are discussing Committee business it is important to have a Government person also to be part of that discussion.

Dr. Dawson: Got it.

Dr. Rice: Della, let me be clear - if this is October 6th then we need to have it to you by the 4th. We essentially have a little over a week to complete all this. Does that seem feasible to people?

Dr. Insel: I think the silence means everyone is already working on this, Cathy.

Dr. Rice: I think if I was just on one committee, but you know, I don't know about two. I could do it in a week, I don't know

about the quality of the work, but if it was one, that would be more doable in terms of real quality and which case since there are so many people on treatment I would move to working with Cindy on the infrastructure and Alison I think also.

Dr. Insel: Well, remember that we can use the 6th to refine and discuss further any of these things. It's really what we are asking for is each of you to take a look at a section of all of the information that is coming through compare it to the plan and comeback with 'is there a need to change anything?' and if so what that might be. And we will work with you to trying to catalog whatever progress has been made. I think you will find it interesting because the portfolio that the team here has put together actually does most of what we have been talking about. It is already organized by objectives and has a tremendous amount of information about where the investments have gone. Unfortunately, it is limited in that

it's a year behind but it still gives you a pretty good sense where we are heading.

Dr. Rice: This is Cathy one more procedure question for e-mails between the work group does Susan or Della need to be copied on those as well, for FACA rules.

Dr. Hann: It would be best to do so. Thank you, Cathy

Dr. Insel: Any other questions or comments about this process?

Dr. Hann: The other things to take into consideration because the time is so short, is while it would be wonderful for the two to three people who are assigned Chapters to be working together, that may not happen. So that each of you may prepare information and come to the meeting on the 6th with each of your sets of input for discussion essentially, so that is another option to consider as well. It will relieve a little bit of the pressure valve.

Dr. Insel: Yeah, we were thinking of the $6^{\rm th}$ as a working meeting not like this is all

going to be perfectly set by that time, but by the 22^{nd} we would like to go to the full committee with something that looks more finalized.

Dr. Dawson: I have one more question on the $6^{\rm th}$ were you thinking of a meeting in the morning?

Dr. Hann: Yes.

Dr. Dawson: Because I think, Tom, I think you and I are both in New York the night before.

Dr. Insel: Yeah, we are. I know, I am actually - I am actually taking the 6 a.m. shuttle back, so I am here by 9:00 a.m. Oh, Okay - maybe we could do this together from New York except I have something else I have to do that day. So we will make it work. Okay.

Dr. Dawson: Alright.

Dr. Insel: Della and Susan, anything else? Is there anything else from the subcommittee?

Dr. Hann: The other thing if you do need

assistance with anything, if you do wish to have conference calls with each other, we are happy to help you with these - to provide assistance with call numbers and so forth like that. So you don't have that expense essentially as well as setting it up. So we are happy to do that as well.

I will try to include all this

coordination pieces kind of information in e
mail what I send out hopefully the first

installment of the e-mail will be out today

and probably the second installment tomorrow

of all the materials.

Dr. Insel: Anything else from the subcommittee? Are there comments? Is there anything else to share with the group?

Mr. Grossman: It's interesting - see what happens.

Dr. Insel: Okay. Well thanks everyone for joining us this morning. I think we have done our work which is to set this process in motion. We will talk to you again in a couple of weeks when we have some of the substance

from looking at all these materials and hopefully we will get all of this to a place where it is ready to go to the full committee on the 22nd. Okay, thanks everybody. Okay, thank you.

Bye Bye.

(Whereupon, at 10:00 a.m., the meeting was adjourned.)