

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

JOINT TELECONFERENCE OF THE IACC'S  
SUBCOMMITTEE FOR PLANNING THE ANNUAL  
STRATEGIC PLAN UPDATING PROCESS AND THE  
IACC'S SERVICES SUBCOMMITTEE

FRIDAY, JUNE 18, 2010

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

PARTICIPANTS:

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

DELLA HANN, Ph.D., Executive Secretary of the  
Subcommittee for Planning the Annual  
Strategic Plan Updating Process, Office  
of Autism Research Coordination,  
National Institute of Mental Health

SUSAN A. DANIELS, Ph.D., Executive Secretary  
of the Services Subcommittee, Office of  
Autism Research Coordination, National  
Institute of Mental Health

ELLEN W. BLACKWELL, M.S.W., Co-Chair of the  
Services Subcommittee, Centers for  
Medicare and Medicaid Services

GERALDINE DAWSON, Ph.D., Autism Speaks

LEE GROSSMAN, Co-Chair of the Services  
Subcommittee, Autism Society

GAIL R. HOULE, Ph.D., Department of Education

LARK N. HUANG, Ph.D., Substance Abuse and  
Mental Health Services Administration

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## PARTICIPANTS (continued):

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

CHRISTINE McKEE, J.D.

ARI NE'EMAN, Autistic Self-Advocacy Network

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

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

DENISE D. RESNIK, Southwest Autism Research &  
Resource Center

CATHERINE RICE, Ph.D., Centers for Disease  
Control and Prevention (For Dr. Ed  
Trevathan)

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

MARJORIE SOLOMON, Ph.D., M.B.A., University of  
California, Davis

BONNIE STRICKLAND, Ph.D., Health Resources and  
Services Administration (For Dr. Peter  
van Dyck)

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

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## PROCEEDINGS

Dr. Insel: Thank you. This is the beginning of a joint phone conference of the two Subcommittees of the IACC - the Subcommittee that's involved with Services and that who is involved with the Planning Update of the Strategic Plan. We've got, I believe, 11 people in addition to myself on the line here. This is Tom Insel from NIMH and I have the Office of Autism Research Coordination group with me here as well. What we're trying to do here this morning is to follow up on the discussion that we had at the last full IACC meeting to plan a workshop that will inform the update. What happened from that conversation according to our most recent review of it was that as topics came up people began to say "well you know we're going to cover that in another meeting" or "there's already another opportunity to hear about that particular topic," so it sounded redundant to

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have yet another workshop on the same topic. What we decided was that we would make sure that as meetings came up on specific topics of interest like therapeutic development, environment, and others that we would send representatives to make sure that there was somebody to report back to the meeting and make sure that the IACC would be informed about new opportunities that could be important for the update of the Plan. It was also suggested that we use our meetings to hear directly from speakers who might be on the verge of important breakthroughs or important new directions for IACC including projects that might be taking place in completely different areas of medicine but that might be highly relevant and at various times we've talked about insights that are coming from cancer or microbiomics or from other areas of biomedical research. All of those things were part of the discussion and, in fact, that was part of what informed the

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plans for the July 16<sup>th</sup> full IACC meeting - the next meeting coming up because that will be a time to hear from a number of different areas of science. Where that conversation went at the last meeting was towards the need for the Services Subcommittee to also develop a workgroup or a workshop of some sort. Even though the Strategic Plan really is meant not to be a plan for services, there was at least a beginning of a conversation that maybe we needed to think whether the workshop we are going to have, sponsored by the Strategic Planning Update Committee might actually be the same workshop or somehow be informed by the workshop that was being thought about by the Services Subcommittee. What we agreed to do is have this conversation today to bring those two streams of thought together and to get your best ideas about how to use the workshop. We still have a discussion about what the workshop would be and I want to clarify that we actually do have a when and a

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where. The When is November 8, 2010 and the where is the Rockville Hilton here in Maryland so the space has been reserved. What we need to discuss today is how you as the two Subcommittees - how you want to use the workshop and what would be the most valuable thing for both efforts - for both services effort as well as the update of the Plan. That's the quick question and I don't know that will take us two hours but I never know how to predict where this discussion will go.

I'll open this up to anyone in the group who wants to just think about what we're going to try to accomplish in this conversation and my one request is that because there's so many people on the phone and there are many, many more people listening in to this discussion if you'll identify yourself when you ask to speak. With that as an introduction let me open up the conversation.

Mr. Grossman: This is Lee Grossman. I do have a lot of ideas and thoughts about how

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we should do this but before we get into any of that discussion I would like to hear from the staff on some more about the logistics. And what I mean by that is the monies that are planned for this program, are they to put on a conference that anybody can attend? Or is it strictly a workshop type of arrangement similar to what was done last October.

Dr. Insel: I'll turn this over to Della or Susan.

Dr. Hann: The understanding that I have from the discussions of the Committee is that it is a workshop but the workshop would be open to the public.

Mr. Grossman: With that in mind, will there be participation from the public or will they be there just to listen?

Dr. Hann: That would be up to the Committee to determine how they would like to use the time.

Mr. Grossman: Okay. Well, I'll kick this off then with some of the thinking that I

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have on what I feel would be the best purpose for this workshop. I think that from the research side that was addressed last October, and it was certainly my belief and I think it was expressed by some others of the IACC Committee at our last meeting, that the general nature of how services need to be looked at goes beyond the research angle. And we have to start dealing with practicality and use the collective nature of the IACC and the fact that there are numerous agencies and interests represented there to utilize that group so that we could best advise the Secretary of what should be done for Service delivery in the United States for autism. With that in mind I would hope that when we plan this out that it will be looking at more at what the specific needs are today that need to be addressed. Ellen and I talked a little bit about this and it seems as though the system is broken, it is not working. It is not addressing the community and as a result

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as a matter to really move the agenda forward for the future for people with autism that we have to start addressing the systems change that is needed today. That's where I would particularly like to see the emphasis of this workshop which is working on how we can affect systems change to better address the needs of the entire lifespan.

Mr. Ne'eman: I just want to say I strongly agree there and I wanted to add that I think this is an opportunity to see the IACC begin to fill the broader nature of its mandates in terms of going beyond the Strategic Plan and advising more broadly into federal activities related to ASD. In that sense, it's my hope that what we can see a discussion on some of the structural issues. And like you said, systems change, but also some of the current crises that are occurring in the service of provisions, looking at the results of many of the budget cuts and the waiting lists going on out there. I think it

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is a unique opportunity to see the IACC add the weight of its recommendations to try to rectify those problems in terms of bringing the focus on policy as opposed to research. I think that's definitely the direction where I would like to see us go.

Ms. Blackwell: I wanted to point out to the Committee that on June 18<sup>th</sup> Della had some ideas that I put on paper because I've been trying to think about how the meeting might actually look and what Lee and I talked about was perhaps starting out the day with the folks who lead the education community and the developmental directors community. I've also been thinking of having Anne Kohler from Medicaid talk, about a topic and I have given this a little more thought. And I think another addition to perhaps just an introduction to the Services system that would add value to this meeting would be to have Dr. Charlie Lakin from the University of Minnesota to set the stage and talk a little bit about

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the National Core Indicators project which could sort of set a national context for how services are delivered in the United States. The Core Indicators data is now looking at about 13,000 people and this project has discovered that about 10 percent of them have an autism spectrum disorder and they are mostly adults. I think Charlie would be a good person to come in and talk a little bit about how people with autism fit into the state system. That isn't on my suggested or initial thoughts that I had about this meeting. Another thing that I wanted to mention to the Committee is that Lee and I went back and reviewed the Request for Information that the Subcommittee issued in late 2008. And sort of as a structural piece, I thought it would be good to look at the top priorities as subjects - there were six top priorities - adults, communities, family support, schools, providers and infrastructure. I know that at least one

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other IACC member was also interested in services research. I guess what I was sort of envisioning is that at least in the latter part of the meeting maybe some track, similar to what we see at IMFAR that could focus on promising practices or exciting things that are happening in those areas including services research.

Ms. Singer: I agree with what Ellen and Lee are saying but I think that because this is a joint effort that we need to keep in mind that we do want to make sure that the discussion leads to a way to really connect the policy and the practice issues that Lee and Ellen are describing back to the research and vice versa, that the research should really be advising the policy and practice. I think it's important that we make sure that we are including a component; we're looking at some of the really cutting-edge services research that's coming out now. We heard a lot of it at IMFAR from Connie Kasari who had

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an amazing study that she did in a school based setting. Paul Shaddock is working on services research looking specifically at transition from high school to adulthood. I know David Mandell has a big study coming out where he is doing work right in the Philadelphia school district itself so I think we might want to consider looking at some of that research work as a way to really advise the policy and practice that Ellen and Lee are describing.

Mr. Grossman: Alison, there's not really much that I can disagree with, but it's just that there is a crisis that is existing today in the service delivery and there are many good models that are functioning well. I would hope that we would really be proactive and address the crisis upfront, and look at research as something that we continue to work on, but that there are some practical issues that we have to deal with immediately that the research right now is not going to get us to.

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If I were to weigh one against the other my scale would tip greatly in the direction of what is policy related and practical and the research would be kind of, for me, just an add-on at this point.

Ms. Blackwell: One thing you might recall from the last full meeting is that Lee and I asked if we could have a presentation on services at every IACC meeting. I've already suggested to OARC, Paul Shaddock, and I believe Lee has suggested someone else, and maybe that would be an additional forum to have those folks come in and talk about the research that is going on.

Ms. Singer: I don't necessarily agree with what you're saying, Lee. I do agree that there is a huge crisis in policy and practice but I think if we're going to solve those problems and talk about those problems it needs to be from an evidence-based standpoint and in order to do that we do need to begin by looking at the research.

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Mr. Grossman: I would argue that there's enough evidence-based information out there now that we can form a basis for improving the policy and the practice.

Dr. Dawson: Just to weigh in here I would hope that we could have not necessarily an either/or but perhaps a balance of both. I think what Alison is saying is that there is research that would actually inform the strategies or the priorities in terms of if you have a large crisis, what is the highest priority or even what is the most effective strategy for addressing the priority. It might be helpful to bring in individuals from other conditions where they have attempted to make large scale changes in the system and through systematic research have discovered some strategies that may be at face value or seem to be a good strategy for a crisis and may not be effective for different reasons and so I think we want to learn from that research in terms of strategies and priorities that

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could guide how to address the crisis. I think keeping that really close link between what the research is telling us and how it informs the best way to address the crisis would be helpful.

Mr. Ne'eman: I think it's very important that we keep in mind that research should be one of the inputs that we consider in the discussion but policy and systems change should be the output. I don't per se disagree with what Alison and Geri are saying but I think we need to ensure that the results of this are that we're undertaking policy efforts. When we talk about including research and taking a research-based approach, I want us to be sure we're going to go beyond simply the medical research model that we've often been stuck in previously. I want to hear, as Ellen suggested, from Charlie Lakin and about the National Core Indicators project. I want to hear from George Braddock, who can talk about successful experiences with

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de-institutionalizing people. I want to hear from some of the work NIDRR's funding on employment. These are practical things that have specific systems change implications. They are somewhat different from research oriented presentations that have dominated the full IACC meeting agendas in the past.

Dr. Insel: Let me just interrupt for a moment to bring us back to what may be a central conflict in this discussion. We are really bringing two streams of thoughts together and maybe they fit together and maybe they don't, but I do want to remind you that in the Combating Autism Act we have been given some quite distinct responsibilities and the research Strategic Plan is one of them but it's not all of them. The section on responsibilities from the Act states clearly that we're responsible for monitoring federal activities with respect to autism spectrum disorder and making recommendations to the Secretary before starting any appropriate

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changes to such activities including recommendations to the Director of the NIH with respect to the Strategic Plan and also in addition, making recommendations to the Secretary regarding public participation and decisions related to autism spectrum disorder.

The Act itself that charged us gave us this very clear line of thought around a research Strategic Plan that needed to be updated annually. Then another piece that has not been well defined but it seems to me that it gives us opportunities that maybe we haven't really taken full advantage of. Part of what we're hearing in this conversation is quite different from our research focus and our research responsibility to make sure if there is a crisis that there is a changing climate that we as a Committee can indicate to the Secretary how that is happening and provide some recommendations about how the federal government might respond to that. When we started this from the last full IACC meeting

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the thought was that we could combine everybody in one meeting, and maybe, that we didn't need to hear a lot in terms of the Strategic Plan Update except on some of the things related to changing Service needs. I guess the real question is for November 8<sup>th</sup> would people be comfortable really using that day for the mandate, or is there still a feeling that we need to tie this more into the Strategic Plan Update or would we be able to get enough from the discussion of the Service needs to be able to inform anything that we want to change in updating the Plan. I hope that gives you some idea why there are so many different perspectives on how we can use this workshop.

Dr. Dawson: I thought Ari said it pretty well, the focus in this context is to help define the problem. It's very important that we know everything that we can know about the nature of the problem from an empirical basis, in terms of everything from ethnic

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disparity to what are the specific health risks that aging individuals with autism are facing. These are all research-based information can help guide what the recommendations are. And second, any kind of research that has investigated the most effective strategies or what are some of the strategies that are being developed. For example, in the area of telemedicine, web-based technology - so the research in this case is not specifically to define future needs for the Strategic Plan but rather using what is known today from an empirical standpoint that could best inform policy and systems change.

Mr. Ne'eman: I do agree we want to use research to inform our systems change discussions but I think it's important to get that research and case studies because that's more what we're talking about. Be focused on systemic change. Ethnic disparity and service provision definitely fit in there but we also

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want to be looking at some of the big picture issues like hearing from the models for autistic adult services provisions that have been developed. Florida and Pennsylvania are two of the states that are undertaking efforts. That's not necessarily something that is going to be published in a journal but nonetheless its information I think we need to have to be able to have a systems change discussion rather than a medical research discussion.

Dr. Solomon: I really like what Geri said about using another condition as a model.

As I think about it we definitely need to make sure that whatever we do has an empirical focus and is research based so that's the landscape the problem and I guess I'm not 100 percent sure of the major issues that we need to address in terms of bringing about a systemic change. Geri did you have another condition in mind that could serve as a model for thinking about this?

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Dr. Dawson: Recently, I attended a workshop that was on aging and autism and it was very informative but one of the speakers that came in was in the area of heart disease and dementia. This speaker outlined the program of research that has gone on in terms of trying to address what is also a crisis with individuals with Alzheimer's and others in a community and how best to provide care. It was fascinating to hear that many of the programs that involved education of physicians, for example, were completely ineffective. The most effective programs ended up being ones that focuses on training the nurses' assistants who are in the care homes. They learned a lot about where you intervene in the system and what ends up actually improving the quality of life for individuals. It's things like that I think we might want to at least be aware of and thoughtful of when we think about systems change.

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Ms. Blackwell: I hear what you're saying and I certainly think that we need to be looking at quality of life, in fact, that's what the Core Indicators Project does, but when we talk about people with autism I don't like to think about the care that they are receiving. I think that it's sort of reflective of a medical model. I think we need to be talking about the services and support that people need to maximize their quality of life in the community - job support and that sort of thing.

Dr. Dawson: Just to translate that kind of idea, if one were to put money into systems change one might want to make sure that there's emphasis on job coaches and teaching assistants and paraprofessionals. That may actually have greater impact than physician training or special educators. The whole idea there is to at least be aware that there are a lot of levels which one can perturb the system and think about improving quality of life and

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what has been effective in the past. It's not taking it literally but more the idea of levels of interacting with the system and what would be most effective in terms of intervention.

Ms. Blackwell: Another project coming out of Dr. Lakin's shop is the direct service worker project and there actually is a module that trains direct service workers in working with people with autism. The other thing that I wanted to point out is the CMS published in March an environmental scan that looked at the research on services that related to people with autism spectrum disorders. I think the most interesting thing that came out of that environmental scan and I mentioned it at the last meeting and I believe it was in everyone's packet and, if not, it's on our contractor Impaq web site right now - what was really startling is how much we don't know in terms of scientific research and services.

Dr. Johnson: I think that's an

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important point that we need to discuss in context of talking about evidence informing our discussions. I think we don't have a lot of evidence of what is working. I think we do, to a certain extent, have to hear from the field about what is going on that hasn't been researched to get us into what does need to be researched and maybe combining that with what we do know from evidence. To the point about looking at other populations I certainly agree that is a good idea and it may be helpful to look at it through the perspective of systems.

So looking at the employment systems and how different populations are succeeding in receiving employment support or again education systems, looking at similar populations and how they're succeeding in the education system. Rather than maybe taking specific scenarios maybe looking at it from the system's perspective and looking at certain populations within those systems. I think in doing that we have to make sure that

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we're looking across the age span because the issues are going to be different in early intervention and early childhood than they are in the adult arena.

Dr. Rice: I'm having a hard time thinking of how we will pack all of this into one day without first coming to agreement on the framework. There's been a clear mandate in terms of the research plan and if we were focused just on the research plan it seems do-able to understand here's what has been proposed, here's promising research or areas of gap and we can inform how to change or update that research plan. It sounds from our discussion that folks are much more interested in not addressing that so much as addressing this large area of opportunity in terms of informing policy and practice. I think we have to go back to how the IACC does that. Do we do that in some sort of document or summary that becomes a recommendation to the Secretary or understanding what would our final product

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from this look like and what do we need to inform that would be very helpful from my view in terms of where we go. Otherwise, we're going to have a lot of excellent random presentations that we don't know what to do with in the end.

Mr. Ne'eman: I very much like what Ellen said about moving the IACC's work outside of the medical model and, in that spirit - and people should feel free to disagree - I wonder if we might use as a framework to structure our discussion for this workshop and potentially to structure our recommendations the four broad policy goals identified by the American Disabilities Act as being the goals of the Nation in regard to disabilities - those being quality of opportunity, full participation, independent living, and economic self-sufficiency. All of the things that we conceivably want to discuss under that scope of systems change including the draft services committee recommendations

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document includes, we need to be discussing under that broad umbrella, and would also have the advantage of moving us beyond simply discussions of the Strategic Plan and getting the IACC to start to fulfill the aspects of the mandate that we haven't focused on in the past as Tom was mentioning.

Dr. Insel: That's helpful but let me just address the members of the Strategic Plan update group that are with us - are you, as a group, comfortable with essentially taking this year's workshop and letting the Services Subcommittee run with it and decide how it can best be used, with the idea that what comes out of this might provide lots of ideas of where we need to focus the science going forward and may provide some gaps, but it is really different from what we did last year. I want to make sure that is okay before we move any further down this road.

Dr. Solomon: I guess I would like to really see a little bit of a fusion because

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Ellen and I spoke about starting the day with someone who would lay out the enormity of the problems and what I'm getting from this call is we could perhaps have a speaker that talks about what the key issues are that need to be addressed and I really liked Ari's idea of about more principles on the broad policy on individuals with disabilities. But in the afternoon I do like the idea of tracking and having some of the people who are actually doing research in the field speak, but have their comments linked back to what set out at the beginning of the day. In a way, we'll be creating dialogue that way and maybe never before have all these kinds of people spoken together in the same room thinking about the same kinds of broader issues. But I think it's actually useful to have research there to hear about the other concerns and I think it may generate a list of questions for us that have a synergy that wouldn't be achieved if we just had one or the other.

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Dr. Insel: Other thoughts from the people on the update of the plan committee?

Dr. Dawson: I certainly agree with Marjorie but I also think in this case the Service Committee really should have leadership in this and they really haven't had the opportunity to be able to develop a workshop like this before. And I know people are very passionate about it and have strong views about how it should be done and in the end, personally, I feel very comfortable with them having the leadership. Those of us who would like to see some of the empirical work presented I'm sure we'll just keep expressing that view, and hopefully that will be integrated to some extent, but I think in the end it's good to give them an opportunity to really run with this workshop, that should have happened a long time ago and it's late in coming.

Ms. Redwood: I have a question and a point to make. I would really like to hear

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from Ellen and the people who worked so hard the last time on the Plan in the area of services and to find out from them whether or not it really is in need of updates right now, or can we leave that open until after this workshop to see if there is something exciting that emerges that needs to be added to the Plan that's not in there right now. I'd like feedback from them because they worked on that area of updates in the Plan and I wanted to go back to the comment that Cathy Rice made in terms of what is going to be our end product here. I do think it would be important to come up with some type of document at the end of this meeting that we would share with the Secretary with regard to the crisis that we're facing right now in country with regard to services. I agree that we don't want this meeting to turn into something where we have all these wonderful presentations but they are not linked to any movement going forward or to change in this environment. I would really

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want to see a product at the end of this meeting that we could utilize.

Dr. Insel: Ellen do you want to respond to the first part of that?

Ms. Blackwell: I think it's great. I'm sure the Services Subcommittee would be happy to work hard on this and I'm glad that everyone has some flexibility. I do believe we can come to some consensus that we can integrate the research piece into what's happening on the ground. And certainly at my agency (CMS) we serve a lot of children and adults with autism spectrum disorders who are Medicaid beneficiaries, both in schools and in the adult world. The State fiscal crisis is having an enormous effect on what is happening in our States, impacting not just people with autism, but all people with disabilities. In terms of the Strategic Plan, we did a really large and very good rewrite just last year and I think in our previous meeting we talked about how it's going to be important not to

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rewrite the Plan every year so we can at least get a mark on how we're doing in terms of progress. There is a need to continue to make sure the Plan is right and I really think we can do both here with this workshop.

Dr. Insel: Anyone else from the Subcommittee on Updating the Plan that wants to weigh in on this? If this is going to be the task of the Services Subcommittee to create the agenda for this, and I think the only other discussion to have what the deliverable will look like because that is something that will come from the full committee. Let me hear from any other members that are on this call from the Updating group.

Dr. Koroshetz: I think it's a good idea to go ahead in this fashion and try to really think hard about what we know is effective in the service realm, what types of studies could be done to try and move things forward. I think the issues of access to services is a real tough one and I think we have to broach

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it. I'm just resonating with what Marjorie said about the fact that this is an issue that is a big problem with all people with neuro-developmental disabilities. I think if we keep that in mind it can have a significant impact.

Ms. Singer: I can't remember which speaker said it but I do think that maybe the members of the Subcommittee on the the Strategic Plan looking at this workshop really from the vantage point helping us identify gaps is an interesting way for us to look at updating the Plan. It's a different way than we've done in the past. In the past we've gone with scientific presentations and trying to move them forward but the Committee struggles with the gaps analysis. I do think the program that Ellen has started to outline would be informative to the Subcommittee on Strategic Planning.

Dr. Insel: Anyone else from the Planning Subcommittee?

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Dr. Johnson: I don't have anything to add because I agree with all the comments that have been made. I think it's an important area to look at, one that we are particularly interested in so I think anything that we can learn by focusing on services would be beneficial overall to people on the autism spectrum as well as other people with other types of disabilities.

Dr. Insel: So it sounds like we have a consensus that the Services Subcommittee will take on this workshop and develop the agenda. We've got a couple of proposals for that, you heard a framework from Ari, Ellen has put forward some specific ideas but could we have some conversation about this issue that both Cathy and Lyn have brought up about what's the deliverable and how do we make sure that this workshop is not just another meeting that people come and listen and go away and maybe plan another meeting afterwards. Is there something more that we can do here to ensure

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that this fulfills the responsibilities that we have under the Combating Autism Act?

Dr. Rice: I think one thing for the Services Subcommittee to comment on is whether the Plan that the Services Committee has put together in the past, is that of use as a starting point. Or do we feel like we really need to start from scratch? This is just a question to that Committee.

Mr. Ne'eman: I don't think we want to discard the recommendations document we currently have but I would argue that is not the type of product that we should be trying to produce from the workshop. I would hope that the product that we would produce from the workshop would be more oriented around some immediate recommendations to the Secretary in the realm of systems change and policy action and the recommendations document is something that we should pick up and continue to work on in the Services Subcommittee's ongoing meetings in terms of a

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broader plan of systems change and policy and recommendations. I say that because there is such a crisis in regards to services in the States right now and there are so many very concerning things happening in terms of budget cuts, in terms of people not having access to vital services that I really do think we need something that is a little bit leaner and more explicit and specific coming out of this workshop.

Ms. Blackwell: Just a clarification to the document that Cathy and Ari are referring to. I think Cathy might be referring to the roadmap, but Ari is talking about a document that the Services Subcommittee started to write that was meant to be a new way of approaching services for the Secretary and we will be talking about that in the upcoming Services Subcommittee meetings. I don't know at this juncture if it's worth going back. Of course is always worth going back to look at the roadmap, but I don't know if the roadmap

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is really the place we want to start with this meeting in the fall.

Ms. Resnik: Having just gone through this process with Advancing Futures for Adults with Autism, I think there might be some things we can learn from the process that we've just gone through. I know that Autism Speaks is on this call have been involved in some level in that process. We are getting ready for a Congressional briefing next month which will be a day prior to the IACC meeting which is a result of a few years of work that we hope will be advanced in terms of public policy. We started with a think tank of about 60 people, just a small group, and I know based on the conversations and what I've been learning from Lee and others that you've done an extensive job this past year of reaching out and learning what has been happening. Perhaps there's an opportunity, I don't know if it's prior to the workshop or if that's possible for a smaller group to come together

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and think through some issues that would create this framework that then we could discuss at the workshop. Going back to ASAA, after the think tank that we hosted, we then worked on some briefing materials and then hosted a national town hall which took place last November and connected 16 cities electronically to participate in this dialogue that we would set priorities in the areas of employment, housing, community life which included services. From that discussion, which included over 1000 people voting and we would prioritize, we've been working hard on extrapolating public policy that we could advance at Federal level and then identify what would be appropriate at the community and State levels. I wonder if there is a page out of that effort that we might be able to learn based on what we have done in the intelligence gathering. And then knowing that we've got this workshop keyed up in November, I'm concerned with how diverse their services and

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demands are and to make sure we establish some priorities and some early successes with the Secretary. Things we can advance that do represent some immediate concerns. But also, identify some of the longer concerns on public policy issues that we want to tee up. And I just wonder again, if we could have a smaller group, and maybe that's our Services Subcommittee that could host some type of think tank so that we can start packaging what it is we want to tee up for the workshop to make sure we manage expectations because we know there are huge demands and I would hate to disappoint.

Mr. Grossman: To Denise's point, I agree that we have to hear from many different perspectives on this and I see the workshop in a very large way bringing many of those perspectives together. There are many efforts going on around the country in looking at the service delivery in autism and in adults at our conference. Most of our conference is

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geared toward adult issues and systems change.

I guess the point is that whenever we do bring people together that should include the greater disability community, because they are an incredibly important stakeholder in this discussion. The emphasis and the focus needs to be on the immediate needs and what needs to be done over the long term. That's how I see it. What do we need to do now to begin to address the crisis and then how do we start working towards this notion of meaningful and significant systems change because the systems are broken and they are not working? There are many people out there talking about this now, but I see this workshop as being one of the first opportunities to bring a collection of very thoughtful people that are working on this issue together and I do strongly believe that there will be some excellent and very meaningful recommendations to the Secretary on how we need to begin to affect the system changes so dramatically and desperately

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needed.

Mr. Ne'eman: I have a question. We're going to be having this workshop and I imagine most of it is going to be taken up by presentations and other opportunities to give information to members of the IACC. At what point are we going to have the opportunity to sit down and hammer out a document and have discussion? With a one-day workshop, unless we can get two days which would be wonderful, but I don't know how likely it is, but with a one-day workshop I don't know what kinds of opportunities we will have for discussion to address policy recommendations to address the current crises. So maybe what we need to do, and I hesitate to say this and I say it should be very time limited, to capture the necessity of urgency here but maybe what we need to here is to also consider what the follow-up process for the workshop is so that we with a quick turnaround get some policy recommendations to the Secretary and thus discuss what those

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should be and agree on what those should be as quickly as possible after the workshop.

Mr. Grossman: I agree - you've nailed what my major concern is. A one-day workshop will not solve the problem and there will need to be follow-up and there will need to be additional work pulled together. I think there's a considerable amount of work that's going to have to be done before November. As well, in terms of bringing people together so that we do have a workshop that does truly reflect the best thinking around systems change and addressing the immediate needs. So I agree, there's going to have to be some follow-up and everybody will have to commit to doing it quickly and have some fairly short deadlines in place.

Dr. Insel: I'm just thinking about the process that we're going to go through here. Since the Services Subcommittee is going to drive this, can I ask Lee and Ellen to pull together what the major themes will be. And

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actually working with the group that you've got, to come up with a proposal for what the workshop will look like? If you bring that to us when the full IACC meets in July which will be the 16<sup>th</sup> of July, so in the next two or three weeks, I don't think it has to be completely polished, but we're not that far off from when we need to send out invitations, so if we want this to take off for November 8<sup>th</sup> we're going to have to move fairly quickly. If we could then firm things up at the full IACC meeting, if you could provide us the basic idea of what this one day will look like in November, and some proposals of who you would like to have participate. We can throw ideas open to anybody who can send proposals to either Lee or Ellen about this. Then the full Committee can vote pretty quickly and move forward and we can make this happen. In terms of deliverables, I just want to encourage the group to be ambitious. We've got a very receptive group in the Department

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of HHS and a very receptive group in the White House and it would be a real shame not to take advantage of this moment in time when there's so much happening to make some clear statements about what the needs are and what the potential solutions are. So if we could think about November 8<sup>th</sup> as being the time to craft that and getting the empirical evidence together and getting the right kinds of proposals about what might be done. This is not the part of the Strategic Plan, this is really the other part of responsibility of the Advisory Committee.

Dr. Solomon: Could you tell us again what our charge is on that second part? Understanding changing climate, I think you said. What we're supposed to help the HHS with?

Dr. Insel: I'll read right from the Act what it says. It's in paragraph 399 where it talks about the Interagency Autism Coordinating Committee and it says first we

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have to develop and annually update of the Summary of Advances, second we have to monitor federal activities with respect to autism spectrum disorder. That means, what is CMS doing? What is available in the way of support at the federal level? And three, make recommendations to the Secretary regarding any appropriate changes to such activities, including recommendation to the Director of NIH with respect to the Strategic Plan. And four, make recommendations to the Secretary regarding public participation in divisions relating to autism spectrum disorder. There is an opportunity here to use the IACC to influence public policy in this area. The Strategic Plan isn't about that. That's really a second responsibility and, as others have pointed out on this phone call, it's not one that we've embraced fully yet.

Dr. Dawson: I just wanted to raise a question in terms of thinking about the topics that are covered at the Services Workshop.

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I'm wondering, Ellen and Lee, if you plan to have some focus on access and quality of early intervention service?

Ms. Blackwell: Education was one of the top six priorities that the public identified, Geri. I think I mentioned that one of our ideas was having Bill East, who runs the special directors come in and talk to us, so certainly that would cover not just the early intervention piece but the entire education piece. Within the topic of education, we can certainly talk about - Gail Houle, of course, is one of our Committee members and Gail focuses on mostly younger children. But certainly that could be a piece of a track that looked at education, which is a big issue for the public.

Dr. Houle: Sure, I would be happy to work on that piece of the services research and perhaps beyond even interventions per se.

We could look at early intervention systems and how they function with regard to access to

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services for children as well.

Dr. Dawson: It does go to some extent beyond what is often defined currently as education so really looking at behavioral health from the point of view of intensive early intervention and access to that and even insurance coverage for that and also the quality and training. Again, there is a lot of innovative work that's being conducted now with looking at different ways of promoting access to early intensive intervention. And I would not want to lose the opportunity to build that into the recommendation.

Dr. Houle: I think that would be a great component of early intervention that perhaps we haven't fully explored as a Committee, some of the issues around the access to that whole system. Because the system for very young children, infants and toddlers, is often, the lead agency for that is outside of education.

Dr. Dawson: Also the level of service

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provided by birth to three in Part C is not meeting what is currently known to be the recommended needs for young children with autism in terms of intervention. Maybe, there needs to be a track or a piece of this that focuses on that because I do think that's something where we could have an immediate impact and have an early win in terms of beginning to change the system.

Mr. Grossman: I agree entirely with you and again going back to what I would hope that what we do in this workshop in addressing this notion of meaningful systems change. We can't address lifespan issues unless we're also doing an extremely in depth discussion around whole early identification/early intervention piece because that's where it all starts. There's so much we can do in that area and it is so fertile and so vibrant right now. There's so much great going on, I almost feel that it's one of those areas that with any little bit of nudging that we could get it on

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the goal line.

Dr. Dawson: Yeah me too. I think it's a low hanging fruit and even in terms of some of the really excellent new methods for providing remote technical assistance. I mean, there's just a lot going on. I'm glad that you're excited about that part too because I feel the same, that we're closer there and so if we could push over the goal line at the same time that we address what is a huge gap at the other end of the lifespan that would be great.

Dr. Houle: We may also want to consider including the medical community on that - the AMA, the pediatricians, who actually have a lot of responsibility for contact that results in early identification and services.

Dr. Dawson: Yeah absolutely, and I think with respect to the medical piece, I really have been struck, particularly as I've been learning more about adult health issues, how critical it is to be aware of the medical issues throughout the lifespan and there are

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major barriers to accessing medical care both from the point of view of access, insurance coverage, and training. It's a huge impact and even looking at mortality rates, which are so much higher in autism, but risks for heart disease related to medication. So I think making sure that the medical community is brought in, even though we're not trying to medicalize autism, is important.

Ms. Blackwell: Maybe a good place to focus might be on the concept of the health home, which is certainly fully integrated into the Affordable Care Act. And perhaps look at places where that concept is working very well for children who have a health home.

Dr. Dawson: And the medical home model early on I think is very important.

Dr. Johnson: I just wanted to add to this conversation. In the medical community, it is also I think important to bring in the early childhood community because often times children are going to be in early childhood

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settings, but health care or early education and they are going to be most likely identified by early care providers. I think we need to look at that issue and what happens to a child once they're identified.

Anecdotally, I think what we're hearing is that most children are then removed from a regular early childhood setting because they don't have support to provide services within the regular early childhood environment. I think looking at that whole issue is an important area and bringing in that community will be critical to this conversation. And again, we may not be able to talk about from a research perspective, maybe from how you provide the services, but I think it has important policy implications for us in this discussion.

Dr. Houle: There are data that we do collect settings data and where children are receiving services. Actually we collect a settings data, birth through 21, so we have it

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for early intervention as well. We don't have to rely on anecdotal evidence, we have some data that's been collected over the years that shows us where children are served, in what age range they are served, where they're served when they're infants and toddlers, where they're served when they are preschoolers, and in natural environments, inclusive settings and that kind of thing.

Dr. Insel: I think rather than trying to plan the entire workshop today. If we can just get an agreement that Lee and Ellen will make this happen and come back to the whole group the middle of July and we can hear more about what they have in mind at that point. Is that going to work for the group and for Lee and Ellen?

Dr. Rice: That sounds like a wonderful plan but one thing I would add is not to jump right to content before we have a framework in mind about what the output is. Ari suggested one, sort of framework in different topic

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areas and then we input across the lifespan to see what areas we need. Whether it's health. Whether it's education. Whether it's community or service coordination. The one thing I don't know about, Ari, the framework you suggested sounded like it is more applicable to adults. Is there another framework? Well one, do people agree that we really need to know what our framework is? Two, is there another framework that anybody knows of that would be helpful to look in terms of needs across the lifespan - we've talked about things like identification and eligibility, access, content, coordination and outcome. They are some key features that we need to make sure we hit upon at all stages of life for people with autism. So just reiterating the need for a framework.

Mr. Ne'eman: I don't think the ASA framework is limited to adults. I think there's definitely applicability. In fact, some of the things that Gail was talking about

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- least restrictive environment - definitely relates to full participation, so there is definitely applicability to children and adolescents. I would suggest is that whatever our framework is, if it's policy goals or something else, that we establish that it is lifespan issues and services across the lifespan is a cross-cutting theme that should come up in every single aspect of the framework. I don't want adult issues silo-ed out into one particular segment of the workshop. I want us to talk about adult issues, adolescents' transition issues, early childhood issues, and aging issues at every single part of the workshop as part of that cross-cutting theme. Regardless of what we choose, and I certainly am partial to the ADA policy goals, I agree that we do need to make certain that we are not silo-ing out particular age ranges and we are considering these issues across the lifespan.

Mr. Grossman: Cathy, I agree entirely

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with what Ari is saying and if we're looking at this - the idea of systems change - it is an aspect that we can't really siphon off any one over the other. They're all interconnected. They all have to be seamless. Even though, for example, we talked about early identification and intervention aspect is being probably some good low hanging fruit. The real crisis is across the lifespan particularly in adult services. The adult service sector is like a perfect storm of inheriting failures of all the previous systems. And then this individual is placed into the adult sector which is inadequate and usually inappropriate to meet their needs, particularly when needs haven't been met for their first 21 years. The way that Ari framed that was very good, in that there's always going to be an underlying analysis and underlying appreciation that every aspect of the system affects the other. And even though we may be talking about one particular

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component at that point, it has to be looked at in the broader implication that it has across the lifespan.

Dr. Insel: Any other thoughts about the agenda that you want to make sure are included by the Services Subcommittee? Not hearing any, if you have any additional thoughts about a framework or deliverable make sure that you convey that to Ellen and Lee and we'll have further discussion once we have something to actually look at where we have a document that we can review from them in mid-July. Are there any other discussion items while we've got these two groups together? We don't have the full Committee, but if there's anybody who wants to put out on the table for either of the two Subcommittees. There's a chance to be heard by both of them.

Ms. Redwood: I have a question about the other aspects of the Plan that we'll need to update as well. You mentioned at the beginning of the call when we first started

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discussing the updates there were several other Committee members who mentioned that they were holding some similar workshops and I would just like to follow up on those two with regard on how we are going to be able to glean information from those workshops and bring that information back to the Committee as well.

Dr. Insel: Great point. We talked about this a little bit the last time we were together and I thought that the interest from the group was two things. First, to have a roster so you would know what was coming up because there are so many different meetings and some are international meetings that aren't often represented on the IACC. And second, people wanted to know whether there was a way to get a report back. So for instance, for IMFAR or for other meeting like that, that are largely focused on autism. Could we have someone who attends give us a summary about the most exciting new

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opportunities, or in some cases if there is a clear gap in our knowledge that would be important for the Strategic Plan to address and make sure we all hear about that. I'm not sure we've done that. We have done the piece of bringing people to the IACC meeting who can talk based on things that we've heard about at these meetings but I don't think we have a structure in place yet for making sure that we cover these meetings ourselves. I assume your question is sort of a call to action so maybe what we can do when we meet in July is to come up with a plan. We can have a list of what we think are the most important meetings and make sure that people are going to cover them and have a chance to report back to us.

Ms. Redwood: I guess the two that I was pointing out are the ones that Geri Dawson mentioned that Autism Speaks is sponsoring. And Geri, I can't remember is that one on treatment? And another one that Cindy Lawler mentioned from NIEHS. So I just wanted to

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make sure that those were on our radar screen and that they would be covered.

Dr. Dawson: Absolutely, I've been in conversations regarding both of those meetings and in both those conversations we've been explicitly talking about how to report back to the IACC so that is very much in front of our minds.

Dr. Insel: Are there others that are coming up in the short term so that we make certain that someone is there for and can report back? Because I think, Geri, your meetings are in September and again in January, right?

Dr. Dawson: The treatment meetings are both going to be in January as it turns out. The environmental meeting, Cindy, are you on the line?

Dr. Insel: No, I misspoke. It was Cathy I was thinking of before, not Cindy.

Dr. Dawson: Yeah, Cathy Rice. This is Cindy Lawler.

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Dr. Insel: Cindy's not with us today.

Dr. Dawson: That meeting, the larger meeting, is not going to happen until 2011. There's a small meeting but it's really more of a planning of the meetings that's been scheduled, but the large meeting won't happen until early 2011. So all of these meetings will be early 2011.

Dr. Insel: But if there are others that people know about, I think the ACE centers are coming together next week. So that might be something worth hearing about. We can make sure someone who is at that meeting can take 5 minutes to explain it.

Ms. Resnik: The July 15<sup>th</sup> Congressional briefing will also tee up a lot of information. We've got four panels of experts will be reporting on issues and also teeing up some public policy agendas in the areas I described earlier. I will be there and I know Autism Speaks and others of you are invited and are welcome to join us.

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Dr. Insel: Denise, I thought we had drafted you to talk to us about this on the 16<sup>th</sup>, is that right?

Ms. Resnik: Yes, I will report back on the 16<sup>th</sup> and also regarding the housing study.

Dr. Insel: That'll be an opportunity because this is really important for the whole group to hear about.

Mr. Grossman: There's a little meeting in two weeks in Dallas - the Autism Society meeting/conference. We will have a day-long scientific symposium on cutting edge environmental health research that we're doing with other disability organizations. They're taking the lead in environmental health and also will have a day-long continuing medical education program dealing with some of these low hanging fruit issues in terms of treatments. There will be major public policy discussions throughout. We're having representatives from the administrations keynote our conference. And they'll be

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meeting of many State agencies and education, mental health and disability. Lastly, there will be a town hall meeting, a fairly large one, discussing the DSM-5 changes.

Mr. Ne'eman: A week and a half from now is AuTreats which is the largest gathering of autistic adults, run by and for autistic adults. And amongst the sessions there, there's going to be Rhonda Basha from the Transportation Security Administration, which is going to include a discussion and a listening session on issues that autistic children and adults face going through airport security. We're currently working with TSA to produce a technical assistance document. Actually it's more a fact sheet for consumers around that, so that may also be of interest to keep the IACC informed on.

Dr. Insel: Hearing all this reminds me that when we started, we use the beginning of each IACC meeting to hear reports from all of the people around the table, but we stopped

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doing that largely because other things crowded the agenda, but why don't we plan to do this at the upcoming meeting. Let's take some time at the onset to hear about all of these things because there's so much going on.

I don't think we take the time to inform each other about what we're all involved with.

Why don't we plan, if we can schedule it. I'm looking at Della and Susan here to take maybe five minutes, or so for each of the members of the IACC to give us a very quick update on their activities, both federal and non-federal.

Dr. Hann: We're a little worried about the available time on the agenda. Another possibility because the Committee is larger, is to think about asking a group at each time - like six members this time and six members next time and so forth. Five minutes for 19 people really adds up.

Dr. Insel: I hear you. We'll work this out but we do want to make sure that there's a

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chance for people to hear about this because there's a lot happening and we need to all be up-to-date. Is there anything else for discussion today? If not, thanks very much for joining us and also thanks to those who listened in from the public. This is a meeting that we set out to figure out how we want to set up November 8<sup>th</sup> and I think we have a pretty good idea about what the themes will be and we'll hear more about the details in mid-July at the full IACC meeting. Thanks everybody and have a good weekend.

(The meeting adjourned at 11:45 a.m.)

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