

U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

SERVICES SUBCOMMITTEE

TUESDAY, AUGUST 10, 2010

The Subcommittee convened at 1:00 p.m., via teleconference, Ellen Blackwell and Lee Grossman, Co-Chairs, presiding.

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ARI NE'EMAN, Autistic Self-Advocacy Network
(ASAN)

DENISE RESNIK, Southwest Autism Research and
Resource Center (SARRC) (attended by
phone)

CATHERINE RICE, Ph.D., Centers for Disease
Control and Prevention (CDC)
(representing Ed Trevathan, M.D.,
M.P.H.)

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PROCEEDINGS

Dr. Daniels: Hi. This is Dr. Susan Daniels from the Office of Autism Research Coordination at the National Institutes of Mental Health. And I'm the Executive Secretary of the IACC Services Subcommittee. So today we're having a conference call of the Services Subcommittee to discuss the planning of the November 8, 2010 IACC Services Workshop. Today I'd like to welcome you all and to remind you that it would be wonderful if we could come to some sorts of decisions about what we want as far as the structure of the meeting and speakers. I know that there is a lot of discussion going on that many names have been put forward, but if we can get some kind of a strong picture of what we're looking for, I think that will help us in terms of planning, because November 8th is not really that far away. And we will be having another Services Subcommittee Meeting on

September 13th, where we can follow up on any unfinished business, but as much as we can accomplish in this short time from 2:00 to 3:30 p.m., Eastern Time, that would be wonderful. So at this time, I would like to turn the call over to the Co-Chairs of the Services Subcommittee, Ellen Blackwell and Lee Grossman. Oh sorry. I should take roll call. Let me do roll call first. Co-Chairs: Ellen Blackwell?

Ms. Blackwell: Here.

Dr. Daniels: Lee Grossman?

Mr. Grossman: Here.

Dr. Daniels: And the members: Rosaly de Correa Araujo?

Ms. Blackwell: This is Ellen. Rosaly will be with us, but she'll be a little bit late.

Dr. Daniels: Okay. Gail Houle is absent. Larke Huang? Jennifer Johnson, but Sharon Lewis will be on the call. Sharon?

Ms. Lewis: Yes. I'm here.

Dr. Daniels: Christine McKee?

Ms. McKee: Here.

Dr. Daniels: Ari Ne'eman?

Mr. Ne'eman: Here.

Dr. Daniels: Denise Resnik?

Ms. Resnik: Here.

Dr. Daniels: Oh great. Hi, Denise.

Ms. Resnik: Hi.

Dr. Daniels: Cathy Rice?

Dr. Rice: Here.

Dr. Daniels: And Stephen Shore and Bonnie Strickland will not be able to join us today. So that is the full roll call. And Dr. Della Hann, Acting Director of the Office of Autism Research Coordination is also on the call, as well as the OARC staff. So Ellen and Lee, please go ahead.

Ms. Blackwell: Okay. Well, this is Ellen. I just want to thank you all for taking the time today to meet with us. I'm in a room at CMS, surrounded by pieces of paper.

So, Lee, I'm sure you feel the same way, because we have been working very hard to try to come up with some ideas for this meeting. And Susan also, you've probably seen a lot of emails and papers coming from her with some draft ideas and some things that we've actually already put on the agenda and on the table, but we wanted to talk with you about. So Lee, do you want to kind of go over the draft agenda, before we start, you know, digging in a little deeper to what we might be doing - as far as who we might be having to talk with us - or in what category?

Mr. Grossman: Well, yes. Much of our discussion that we've been having amongst Ellen and Susan and I have been the result of the presentation of what was done at the last IACC Meeting and getting people's feedback in terms of how to move forward with this, and then also getting clarity around some of the logistics and the timeframe of what this workshop will be like. We know that it's one

day. We know that we've been charged to come out of this to be able to put together some format to make recommendations to the Secretary. Tom -- Dr. Insel made it very clear that he had hoped that this workshop will produce recommendations that would have significant impact on public policy. And as a result of that, we've put our minds around this, trying to actually make that happen. It's a big task for us to be able to do a workshop in one day that will significantly impact public policy, but it's certainly something that we're all committed to do. We took the six highest priorities that were identified - Excuse me, I've got things buzzing and everything at my desk. Sorry, but it's distracting for me. And hopefully it's not for you. We took the six highest priorities that were identified in the RFI that was issued last year on what people wanted to see placed in the - or wanted to be addressed in autism services. And from that,

we started to pull together a list of names that would fill those categories. And what we've come up with - and we certainly want feedback from the Services Subcommittee on this - is that we want to have speakers come in - and we'll probably have three, maybe four, speakers in each of the six categories throughout the day that would be addressing these three key themes. First of all, systems change over the next decade; cost-effectiveness; and then building a seamless system of quality services and supports across the lifespan. Again, the goal is to formulate recommendations of addressing these issues so that we can present these to the Secretary of Health and Human Services.

Ms. Blackwell: And I would add that some of you who previously served on the Services Subcommittee might recall that one of our projects, that was somewhat interrupted last year by the intense work that we did on adding a lot of - updating the Strategic Plan

- was to take the roadmap that the previous Services Subcommittee had written and update it into perhaps a series of recommendations, as Lee said, for systems reform to the Secretary of Health & Human Services. And perhaps also - I'm not sure yet. We can talk about this today - to the Secretary of Education. So that's kind of our focus, the things that we would be looking at are, you know, as we talked about in our last full meeting, most of the States are struggling with severe fiscal crises that are having an impact on all sorts of services, including services to people with developmental disabilities and specifically to people with autism, within that category. So we believe that this meeting could really go beyond what's been done in a lot of other meetings and take a look at how this contraction across the country maybe can be used in a positive way. So, Lee, wouldn't you say that's what we're kind of going for here? That that

really hasn't been done yet.

Mr. Grossman: Right.

Ms. Blackwell: And so that's part of the context of the reform that we're looking for.

Mr. Grossman: Yeah. And we're very aware of the fact that to accomplish this in the course of one day is going to be very, very difficult. We haven't addressed yet what the follow-up measures will be in terms of putting together the recommendations. And we haven't done that purposefully because we want input and suggestions from the Services Subcommittee on how to do that. We're going to have to take those, whatever we decide on as a Subcommittee, to the full IACC -- it's my understanding - for them to agree on how the follow-up will be and the process that will go beyond what comes out of this one-day workshop. And let me go through very quickly the draft agenda for the conference on November 8th. What we were looking at was to

start the day off with an introductory session so that people can kind of give us the lay of the land on what's happening out there. And the three recommended speakers are speakers that we came up with that we thought could do a good job of that were Nancy Thaler, who is the Executive Director of the National Association of State Directors for Development Disability Divisions. And one of the other speakers is Bill East, who is at the equivalent level with the National Association of State Directors for Special Ed.

Ms. Blackwell: And those two folks are really at the head of what we believe are the two systems in this country. We didn't bring in Voc Ed here, but we think that Bill and Nancy can talk a little bit about how the, you know, what's happening now, what they expect to happen in the next 10 years within the education system and the developmental disabilities system, and also sort of frame that within the context, as I said, of what's

happening to States as their budgets are contracting right now. Lee, do you want me to talk a little bit about Charlie Lakin?

Because I -

Mr. Grossman: Yes. Yes.

Ms. Blackwell: Yeah. Charlie Lakin is a Professor at the University of Minnesota. And I know that Ari, you're well familiar with Charlie. But Charlie and I have talked a little bit about a project that Nancy sponsors and started called the *National Core Indicators Project*. And it looks very closely - there's a website that folks can look at quality of life indicators. It's sort of the beginning of what CMS will be working on in terms of adult quality measures. And Charlie is in charge - or knows a lot about that project - And he also has some interesting data on people with autism within the *National Core Indicators Project* that I think is really interesting that we haven't heard before. But Charlie also has a different role. He is very

heavily involved in the Direct Service Worker Project and the training modules that infuse people with education -- In one instance, a module that is aimed at people with autism. So Charlie, I'm thinking, could actually have a dual role in our conference. But I thought we should definitely give him some time to talk about what the DD system looks like for adults and also what it looks like, specifically, as far as what we know about people with autism in the DD system. So do those three sound like something that our group is on board with to sort of kick off the day?

Ms. Lewis: This is Sharon. And I think that makes a lot of sense. And I would add, in terms of the endorsement for Charlie - You know, ADD has three longitudinal data projects and actually has been looking also at the National Core Indicators Project. And Charlie runs one of those data projects for us in terms of looking at quality of support, doing

analytical work around residential and services, and has an excellent sense of not only the direct care components, but data and systems broadly. And I just think that's a great perspective to have him bring to this table.

Ms. Blackwell: Oh, that's wonderful, Sharon. I've had some conversations with Charlie about this meeting in particular. And, you know, I also think that he could sort of set the stage for how the economy is changing what the services outlook looks like, you know, in terms of, you know, waiting lists for Medicaid waivers, for example, and the kinds of steps States are taking and what maybe that looks like - And I don't know if it's the short haul or the long haul, but he's so great at explaining that. And we at the IACC have not really heard that. So I think Charlie - I also agree with you. I think he'll bring a lot of value you to this meeting, in terms of just helping people

understand what it looks like out there.

Dr. Huang: Ellen? Ellen, this is Larke from SAMHSA.

Ms. Blackwell: Oh, great. Glad to hear from you, Larke.

Dr. Huang: And I think, as you described each of them - I don't know the speakers, but they sound great. I have a question in terms of - And I see the key themes that are systems change, cost-effectiveness, and building a seamless system of quality. I'm wondering if, on the IACC, we have a good sense of what is the system of care and services needed at different points of the developmental lifespan for kids or children, people with autism.

Ms. Blackwell: Well, back in November of 2008 - And I know, Susan, you have a copy of it - I actually put together a presentation that talked about - Now, it's a little bit outdated, because of the changes that have been made and the statutes that have been made

and that are coming through the Affordable Care Act. But I do think that that presentation does sort of a good overview of how the services system in the United States works. So maybe that's something that, Susan, you could send around to the Services Subcommittee members. Would that be helpful, Larke?

Dr. Huang: You know, I think so. I guess I'm trying to step back and think what is a good, and now 21st Century or 2010 or 2011, system that we want to build for the right services and supports? What exists? What would be a very good one? How does health reform come in and kick in and support aspects of it? So I think we're hearing from different pieces of it, but I'm still wondering if there is some kind of overall framework with some set of clear, guiding principles around what type of supports and services and what they should look like across the lifespan.

Mr. Grossman: Well, to respond to that, Larke, I think that's the purpose of the workshop is to determine what it should be in 10 years. In our previous conversations, we've - Correct me if I'm wrong, but it seems as though we've come to the conclusion that the systems that are out there now really aren't working well. They're certainly not seamless. They're not comprehensive. They're disjointed. And that's where we want to get to is having a workshop that will start developing the type of recommendations to build the system that is necessary. I mean, there are some models. And that's something that we've struggled with when we've talked about this. Do we want to identify models now, that seem to be good models? Or do we want to start looking at what we hope the entire system will look like in the future? And because of the fact that we only have the one day and it's such a limited time, we thought that we should just focus on creating

what we think would be the best system of care.

Ms. Lewis: Lee?

Mr. Ne'eman: This is --

Ms. Lewis: Go ahead.

Mr. Grossman: I think it was Ari?

Mr. Ne'eman: Yeah. I didn't mean to interrupt you. You can go before me if you want.

Ms. Lewis: Well, this is Sharon again and I guess what I would say is I think, you know, Larke, I think there is value in terms of laying out what there is, with an acknowledgement that that may not be what we want or that we'll help to begin to identify, to Lee's point, by the end of the day, you know, what could be. So in terms of this first session, lay of the land, I think that, you know, having this perspective from, you know, Nancy Thaler certainly is going to be able to provide kind of a birth to death perspective of what are States doing in the DD

systems around people with autism. What does it look like from a waiver perspective? And then, you know, Bill certainly will be able to talk about birth to 21. I think that the one piece, if we were talking about lay of the land, that I see missing, and I understand that, in terms of brevity, you know, it's hard to bring all of these pieces together simultaneously, is the conversation around employment. And I just wonder - you know, I mean Charlie will be able to touch on that a little bit. And Nancy will be able to touch on that a little bit. But I think that that's the other leg of this table as you're laying out what the framework might look like in terms of a lifespan framework.

Mr. Ne'eman: This is Ari. I guess the one thing that really comes to mind here is it seems like from the introductions, we do have that broad understanding of what's happening now and the real priority, in terms of what the IACC has not done in the past is to look

at the systems level of things. You know, in terms of the whole though, I mean, I think employment is definitely one area. I almost think that's sort of a subcategory of a larger gap that currently exists, which is people who are not eligible for Medicaid funded services. Though I think we do need to focus on systems. And we do need to work in employment. But you know, I would encourage -- particularly in those sections around adults, community and infrastructure -- us to look at systems change models and capacity building models that will hit at those under-served and really unserved populations that just don't have anything available to them right now.

Mr. Grossman: Before we go on, if people don't mind, let me go through the rest of the draft agenda. I think then we can open this up to a broader conversation. Because there's just a couple of other things that we want to key in on in this agenda. It won't take more than a minute or two. After

Charlie, the next session that have would be that first, one of the six highest priorities of adults. Now please understand that these are not listed in any particular order. The six priorities being adult, public community, family support, early intervention, providers, and infrastructure. So we can move those around as we feel necessary. What we wanted to do was then break up the morning and have, prior to lunch, to hear from somebody high up in the Administration. And that's why we have, as a holder here, either Michael Strautmanis or Jeff Crowley, to talk in terms of really what the Administration, how they see this and to get their input in this and hopefully their encouragement of what we're doing, which I would think that they're doing. And then after lunch, we'd go through the other five priorities. Again, they are in no particular order. So that's the draft agenda as it sits. We have a very limited time at the end of the day for synthesis and wrap-up.

We obviously need to do that at the end of the day. And I have a feeling that if, for this type of conference, we could probably have it go all week and still not cover the breadth of information that's there. So we're trying to squeeze as much in as we can in a nine-to-five day.

Ms. Blackwell: This is Ellen. Before we - Thanks for bringing us back to Earth for a second here, Lee. Before we go too much further, I think that we would both like to hear two things: One, do you have any preferences or other ideas, as far as a speaker, Mr. Strautmanis, Dr. Crowley, or is there someone else that the Subcommittee thinks would be appropriate? Number one. And number two, when Lee and Susan and I were talking about the way this would look, we were envisioning these topics as panels with two or three presenters. So we want to make sure that you guys are okay with that. That you think that's a good direction. Again, it's

squashing a lot into one day. But that's kind of the approach we were taking and we were going to ask everyone to be as brief as possible in their presentations so that we have time to ask questions when we have these topic panels, which, you know, could quite frankly range pretty far within these rather broad topics. So does that - does this sound like a good direction? And how do folks feel about the lunch speaker?

Ms. Resnik: This is Denise. And I'm obviously new to the committee and I know I have a lot to learn. And I'd like to - Before I could comment on whether that's a good direction, Ellen -- if we could go back and concisely articulate what is it, at the end of the day, we would have hoped that this workshop would accomplish. And then use that as the litmus test for how we evaluate - You know, excellent speakers, but do they get us where we want to go? And if this is going to then inform a further subcommittee for the

public policy recommendations - I'm just trying to get my head around it so I can be helpful and contribute to where we want this, you know, in a series of efforts that have been made to try to, I believe, meet up for these public policy recommendations. But can you help me think that through?

Ms. Blackwell: Do you want me to try to give you a couple of possible examples, Denise?

Ms. Resnik: Well, I'm trying to figure out how best to evaluate the things that you - you know, the people who you've identified, as well as - I mean, obviously the topics come from, you know, what we've heard. But you could go in so many different directions. And I know that's one of the challenges before us. And so maybe if we took just one of them. You know, maybe we talk about adults. I know that's we'll spend 45 minutes on it, according to this schedule. What issues - you know, what would be those two or three pressing

issues that we believe have the best chance of being able to, you know, work their way into meaningful public policy, you know, changes, because we're going to be shining a light on them. I'm just trying to get my arms around it and I appreciate your helping me.

Ms. Blackwell: Um. Okay. That might not actually be the easiest one. But I'll -

Ms. Resnik: Well, pick an easier one. Pick an easier one.

Ms. Blackwell: The first one. Let's use one example that Susan, Lee and I have talked about and that would be the example of how self-direction can, not only be a cost-effective practice, but for the individual being served, for a State, for the Federal Government. Only some States offer self-direction in their programs. So let's say a potential recommendation might be that somehow States are encouraged or directed to include self-direction in their programs. So perhaps we could look at, during our - And again, I'm

just sort of coming up with this on the fly, but we could get a State that's using self-direction, say, Michigan, a State that employs self-direction in all of its programs to show how that's been cost-effective for the State, how it's been satisfying for consumers of State and Federal services. That's just one example. Did that help at all?

Ms. Resnik: Yeah. That helps. And what you said earlier in terms of cost-effectiveness, lifespan concerns - Again some litmus tests and somebody earlier talked about guiding principles that would help us evaluate, you know - And again, the short-term opportunities that we have to affect the public policy. But we - You know, some of it, we're not going to be able to take on at this point in time. So where can we be most, where can we create the greatest impact and be successful and then building on that for the future. I guess that's where my head is going and that would be helpful for me to be able to

weigh in on speakers or topics.

Mr. Grossman: Well, and that's - This is Lee. And we also talked about putting the key themes to the key speakers and the people that we invite. For them to come to us with what they recommend would be the best way to address the themes that we put forth. And that's why it is so important for us, as a committee, to choose who we think will be the best people to really come to us to make these recommendations. We didn't want it to - Because of the limited time that we had, we didn't want it to be really people presenting so much of what they're doing, we want some strong thought leaders to come forward telling us what they think the future should be like and how to create that.

Dr. Rice: This is Cathy Rice. I just - I guess following up on what Denise is saying I think I'm sharing somewhat of the cloudiness in terms of the product still and that the themes are very helpful. But is it possible

then to then expand each of these themes to be a particular goal? And then kind of how the old services roadmap was structured was talking about each goal, the challenges associated with them, and specific recommendations to address that goal. And maybe another aspect to include in there would be sort of opportunities - you know, kind of how the general IACC Strategic Plan has focused on. Well, what are some of the current opportunities happening within that particular goal? So if we're talking about systems change, what is our overall goal there? What kind of things are happening, as opportunities? What kind of challenges exist in terms of having systems change to meet that goal? And then what specific recommendations? And then if each of the panel could sort of comment in those themes, maybe they have a different - You know, maybe they're talking about early childhood and another member of the panel is talking about adolescent

transition services, and another member of the panel is talking about adults later in life services. I guess I'm still feeling the need to put a little more structure.

Mr. Grossman: Uh huh. Yeah, I -- This is Lee. Cathy and Denise, I think your suggestions are very valid and great suggestions. I guess what we've been struggling with - What Ellen, Susan, and I have been struggling with is the timeframe that we're limited to here. And do you think that what you're proposing will - that we'll be able to do that? Or can that - or do you think that that would be - that that would create the need for her to follow-up post conference.

Dr. Rice: I guess for me - To me, it helps it be clear about what we're going to get out of it.

Mr. Grossman: Okay.

Dr. Rice: If we're asking for recommendations based on each of these themes,

and then across the stages of life - and then in the end, we'll come up with - well, here are kind of our opportunities, challenges, and recommendations. And that's essentially the report.

Mr. Grossman: Um hmm. Okay.

Ms. Resnik: Cathy, I like where you're going with that. And that would help me then to have input in terms of, you know, speakers. And I think creating topics that are timely, relevant today, you know, we're all suffering with the economy and all the States are being stressed. I think having, you know, those factored into these discussions - We know the whole lifespan service concern has been with us and will continue to be with us, but where can we make the greatest impact in the shortest amount of time? And to your point, Lee, in terms of follow-up, I agree that there will need to be follow-up. And I think that, as part of this committee, we need to determine what those steps will be following

this workshop. But for there to be actionable steps - Here are the questions that are going to be answered - you know, that we're going to be addressing - or the questions and concerns we're going to be addressing, and then here's how we're going to take the information from the workshop and participants and what we do as a committee - and be able to articulate how this information is going to be used and how we might be able to call upon those speakers in a next-step effort.

Dr. Huang: This is Larke. I just want to say this is very helpful. I just also want to suggest that we in some way connect up with the Strategic Plan, the IACC Strategic Plan, because I feel like we're always kind of looked at as - and in addition to the Research Strategic Plan, there is a Services piece. And I'm wondering if we key in to, starting with question four in the Strategic Plan, which is which treatments and interventions will help? What does the future hold? Where

can I turn for services? What are the other infrastructure needs that must be met? I think if we kind of align it like we're really integrally a part of the Strategic Plan, and services is not always front-and-center in that Strategic Plan, I think that we might actually get more buy-in from the IACC if we can say this is now augmenting the Strategic Plan with a really critical services piece.

Mr. Ne'eman: Larke, what may -- This is Ari. I actually sort of have to respectfully disagree. Or at least I have some concerns around that. You know, the purpose of the Strategic Plan seems to be focused around research. The way our mission is structured, we deliver the Strategic Plan to NIH. And I think what we really want to accomplish with this is to deliver policy recommendations to the Secretary. And you know that's really a very different kind of deliverable to a very different kind of consumer. And I guess I just - you know, I agree with you. Very

often, Services Subcommittee is viewed as, "and also." And I think we want to avoid that. Viewing this work as sort of a subsection of the Strategic Plan, though, I think would play into that. And that would be where my concern would lie.

Ms. Blackwell: This is Ellen. I have a question then, because I'm thinking a little bit differently now in terms of our key themes. Maybe, Lee, we don't need to focus on these topic areas, but we need to focus on our key themes. What do you folks think about that?

Dr. Rice: Yeah, I guess for - This is Cathy - saying, well, within each key theme, what is meant. And some of those topic areas will go under that theme. So how I kind of - I guess I think in kind of grids, Ellen, in that, for theme one, systems change over the next decade - So one proposal would be then to also split it out by lifespan - you know, I would propose and people can shoot this down -

but early childhood, school age, adolescent, and then adulthood, meaning through geriatric you know -

Ms. Blackwell: Actually - Oh, I see what you're saying, Cathy. But are you thinking in terms of the next -

Dr. Rice: Well, the next decade. But how do you do systems change for adults - systems change for school age adolescents, systems change for early childhood. Maybe in some cases the goal may be the same. So what would be the goal and are there different goals for different lifespan time? So what's the goal for early childhood systems change? What's the goal for school age adolescents? What's the goal for adults? And then within each of those, to meet that goal, what are the opportunities happening here? What are the challenges? What are the recommendations? So if we're talking about systems change in the next decade for adults, there have been a lot of excellent speakers proposed, talking about,

you know, Medicaid issues, vocational issues, housing issues. You know, what's the primary goal we're talking about in terms of the system? Is it more the seamlessness of the system here? You know, really narrowing down what we're talking about. And then we pick the speakers to be able to meet that goal and identify the opportunities, challenges, and recommendations, and meeting that goal of systems change for adults. Does that make - I'll just throw that out there for discussion.

Dr. Huang: I think that's a great, while that's a great suggestion, I think what we keep coming up against is the reality of the time constraint that we have and how deep we're going to be able to go on those topics. I like the idea of thematic, possible thematic or using the categories that you have now for, you know, adult education, community, all of those. And having maybe - You know, because prepping topics under each. And you know, I'm looking at the Strategic Plan right now and I

do believe that we want alignment. I mean, I'm in favor of creating some alignment, however that looks with where the Strategic Plan is telling us we need to go, we're going with this workshop in our public policy recommendations. But I do think we need to connect the dots here on this part of this effort.

Ms. Lewis: This is Sharon again. And it strikes me, as we're walking through this, that, you know, this is a - I appreciate that we have one day and this is a highly, highly ambitious agenda under whichever way you slice it up, whether we do it under that six priority areas or you do it over the course of a - you know, in looking at it through a life course lens in terms of systems change, that drive us towards cost-effectiveness and the seamless service system across the lifespan - Effectively identifying and acknowledging and having any discussion about any one of those topics is pretty substantial. And I guess my

feedback would be, you know, I wonder if we need to simplify the breadth of the service system pieces that we're trying to address because that's a lot in one day for any of us to take on. And I think that if, again, depending on the goal, if the real goal is policy recommendations to the secretaries, focusing on the intersections of the variety of the components that come together in any one of these life course areas. So for example, if you were going to talk about kids that might be a combination of education and family support, service provisions through a human services lens of you know D.D. or autism services might be one, that in itself with the various systems that impact kids and families at one point in time is a substantial conversation right there. And I guess if were going to stay with this broad birth to death approach I would see organizing this across the life course as a way to then really get the policy conversations that acknowledge

those interdependencies. You can't have a conversation about adult services without talking simultaneously about Medicaid, housing, employment and family caregiver support. So if you were going to organize this into panels of 2 or 3 folks, it may make sense to do - and we're trying to prioritize - policy arenas, organizing against the life course and then potentially reducing the scope of all the different issues we're trying to address simultaneously may be the better policy recommendations at the end of the day.

Ms. Blackwell: Thanks Sharon. This is Ellen. I would like to add that the one piece I think we don't want to lose is infrastructure - which sort of crosses everything, even if you look at this from a life span perspective, when I started looking at speakers and getting ideas about where changes might be necessary in terms of policy, they were almost always in terms of how they are managing their infrastructure. And I

think that cuts across systems, right?

Ms. Lewis: Absolutely.

Ms. Blackwell: So if you box it out and say we're going to talk about the providers in one session and family support in a different session. Both of those systems have issues related to infrastructure that are interdependent.

Ms. Lewis: Well maybe the speakers should just be speaking to the 3 key themes? You know maybe that is another approach to take, to just say, ok, let's focus on these 3 themes. And not disperse to death because I'm with you I think you start crossing over the minute you divide it into children, use and adults. I don't know and I really would hate to lose infrastructure because that's where the really exciting things are happening that do have the potential to transform many of the systems that serve people with autism.

Mr. Ne'eman: To a degree isn't it the lifespan approach that allows to look at the

ways in which different policy issues are interdependent? I mean if we want to look at the way in which the school systems interacting with the voc rehab systems interacting with the D.D. systems and so on and such forth. Shouldn't we be looking at panels that focus on adult, on early childhood, on adolescents? Won't that lifespan approach allow us to make connections across different types of service provision systems that people are accessing at different points in their life?

Ms. Blackwell: I think that the concern Ari is that I think you're right, I think though that if we're going to go that route, it may be useful to kind of think of what is the one thread that's going to lead us to policy goals. Because I think that given the limited amount of time that we're talking about, you may end up with a wide ranging conversation that doesn't drill down to where the tension points in the system and in the

infrastructure and in the silos that allow for better outcome at point x, y or z. And I think to try and do that across the whole lifespan in one conversation is tough.

Mr. Ne'eman: Ellen I agree with you 100% around that. I guess what I would say then is we need to look at - I don't think any meaningful conversation can happen in a day. I think we need to look at the workshop as a beginning and I think that before we could really decide what the workshop is going to look like, we have to figure out what follows up after it. And in this sense, I really that that what we don't want to become is subsidiary of the strategic plan. I think we can learn from the process the strategic utilized in order to develop it. They split into panels, but they had their panels do work after their initial presentations and report back. So I guess I think it might be interesting to dissolve some of these issues by having a discussing that gives us an idea

as to what going to happen after the workshop to turn the presentations, whatever the structure they have into some kind of policy recommendations.

Ms. McKee: This is Christine. We've been talking for a while looking at the road map and trying to figure out if this committee wants to take that and do some type of a parallel of strategic plans and services, with very specific short term and long term goals and opportunities, pressing topics and start picking off some of this low hanging fruit. I guess I think we kind of need to decide if that's where we're really trying to go with this or whether that is, as Ari says, our next step down the line after this conference. Because I've struggled, every time we read the road map it's completely applicable today and it's so large and daunting, and the issues - where do you even begin to break that down into specific goals and opportunities? I think it would be very beneficial if we

brought in speakers to kind of crack that egg for us, even if there just looking at those categories. And start getting into some specifics so that we can start to take those next steps, instead of saying that the broad level that we're at right now - where the problem is just so large we can't really do anything.

Ms. Resnik: I think both of you have made excellent, this is Denise, excellent suggestions in terms of figuring out where this takes us over the course of whatever couple of months and whether we can create a process to get us to our strategic plan, more specific strategic plan that includes public policy recommendations. And you're absolutely right in terms of the reason we haven't made perhaps greater progress in this area because it is so daunting. And I think kind of manage some of our own expectations in terms of what we can achieve could be very helpful along with some specific areas of focus perhaps

under each of those categories, that could be very helpful too. So trying to figure out where we can do to make manageable for us. And then back into what this workshop will represent in a series of other efforts that obviously involves my participation.

Ms. Blackwell: This is Ellen. Do we want to start...I have ideas about speakers to who might be able to sort of head us down the path of systems reform, but I'm not quite sure where to go. Do you want to start talking about some of the speakers that we talked about earlier and that folks suggested? Or take a step back? What does the group want to do?

Dr. Rice: This is Cathy. I think the question raised about the first decision is, is this workshop meant to be all encompassing and at the end we're going to have a product? Or is this the start of a process? I think we're kind of avoiding that's a really hard question and we'd really all like to be able

to come together so nicely. But I'm just feeling the pressure that that's such a big issue and too much to do in one meeting.

Mr. Grossman: This is Lee. I've been perfectly quiet because I wanted to keep Susan, Ari and Ellen have been kicking this around for a while and I wanted get other people's input. To the question you just asked Cathy. I think that realistically it's impossible - over the course of one day - to be able to have that goal immediately met. Even though we don't have any further charge at this point beyond that one-day workshop, it can be a recommendation from the Services Subcommittee, I believe it can be, through the full IACC that we will look at this workshop as a one-day event to get the process started. And I'm not sure if we're going to have the answer today, but maybe at the next time we convene, which is in a couple weeks, is that we will have a suggested follow up to this workshop. Does that sound reasonable to

people? Because there's just no way, in one day, that we're going to be able to do what we haven't been able to do in years to put and get to and to embrace this and really address the enormity and complexity of this issue.

Mr. Ne'eman: Lee, this Ari, and I think not only does it sound reasonable it sounds absolutely vital. We can't have a meaningful conversation as to what the start of the process is going to look like if we don't know what the rest of the process is going to be in the question of basic way. So I'm very excited and very much in agreement that we put some serious time in our September meeting to figure out what the follow up and what the broader services policy recommendation process is going to be, kicked off from this workshop.

Unannounced Female: I'll second that.

Ms. Blackwell: Well in the meantime, I think that the problem facing Susan, Lee and me is that we have to start getting the agenda together pretty quickly because obviously we

have to start inviting people to participate.

Ms. Lewis: So can I jump in here. This is Sharon. I guess what I'm hearing folks agree on is that we think that this is really a starting point in terms of the conversation. And therefore, given what we already know, given the roadmap, given the enormity of the task, given the strategic plan. What do we hope, if each member took time to think about, what is the one thing if you were able to walk out of this day, what is the one thing you would like clarity around in terms of what bringing all these folks together provides you. Is it more along the lines of that lay of the land? Is it options? Is it infrastructure issues and where the systems fall down? It seems to me that if we could coalesce, I mean I think that again from going back to the themes of systems change, cost effectiveness and seamless services systems across life span. Well those are laudable themes and things that should be a component

of everything that we're talking about. If we could narrow in a little on bit about what is it, if this is the first step, that we want to walk away with? It makes it a lot easier to say ok, if we're going to do a panel related to early intervention then that may be a combination of the lay of the land and the best practice is panel if our goal is to come out with specific recommendations around early intervention. But some of these topic areas, let me just say, services to adults. I think that that's harder to get to that level of specificities. So coming up with a goal of what this day is intended to do and be, could provide the clarity that would then have all of us help you get names for these panels.

Ms. Blackwell: So Sharon, this is Ellen, I think we may have the lay of the land down in the morning. So I think that piece might be taken care of so

Ms. Lewis: Can I interrupt for one second? I would say that that's the big

picture lay of the land, but if you're going to start a conversation about family support. And it's timely and it's the topic I'm going to pick on for a moment.

Ms. Blackwell: No it's a topic, go for it.

Ms. Lewis: It's a big issue for us in the DD world at large, right? And part of the lay of the land that has to be informed around, part of the conversation in order to even have a policy debate about family support is getting to a lay of the land around family support. And what does that mean and when we say family support, are we talking about birth to 18, are we talking about family caregiver support for each 18 plus, what are we talking about? And there are definitional issues in there that could take up 2 hours just right there. So again is the goal of a family support conversation in this policy context around laying out what we know that's happening in family support for families of

people with autism. And then from that where there are gaps or what is our goal in that smaller conversation?

Ms. Blackwell: Well no, I think that in this day, as you said, we could spend 2 hours just on the lay of the land for each of these 6 topics. So what if we did a quick lay of the land and then several best practices that could be systems best practices? Does that sound reasonable?

Mr. Ne'eman: I almost think that, I mean I think that does sound reasonable. I would think about perhaps seeing if there's any way that we can make available to the Services Subcommittee and to the full IACC, if the full IACC is participating, some materials around the lay of the land beforehand, so as to maximize the opportunity to identify what are the low hanging fruit policy recommendations - where a nudge from the IACC may actually be able to do some good.

Ms. Blackwell: Is that something the

Services Subcommittee members could work on in those 6 areas ahead of time? I mean, does that sound like something the Services Subcommittee could do so there could be a briefing, a one page briefing sheet in the packet to sort of frame that panel?

Mr. Ne'eman: With working with OARC, I think we could provide the leadership and some of the work around that. I don't want to volunteer people, but I know I'd be willing to help around that.

Dr. Daniels: So this is Susan, if the Subcommittee members want to write briefing sheets, we can format them in OARC, but we can't do briefing sheets for you on all these topics. Unless you just want us to collect information that's available publicly that's already on the web. But we can't create briefing materials for you.

Mr. Ne'eman: I think the Service Subcommittee can find a way to make and get materials together. Whether is putting

together brief new materials or identifying good compilations in advance that are already out there.

Ms. Blackwell: Well I would actually suggest no more than one page on each of the areas. I think that would be enough to sort of set the stage. I think one page is enough.

Mr. Ne'eman: I definitely agree with you. We're not going to get people to read. Most of the IACC members that aren't as engaged around some of these issues, we're not going to get people to read that much more than one page.

Ms. Blackwell: And that could be set up as issues and background. One page.

Dr. Daniels: This is Susan. If you decide that you want to do that, you might want to have different Services Subcommittee members each volunteer to write a brief. And then OARC can collate and format all of that and get it out to the people that need to have it.

Ms. Blackwell: And that would devote more time to looking at best practices as Sharon has suggested.

Mr. Ne'eman: That could work. Yeah.

Ms. Blackwell: Are people comfortable with that approach? Lee, are you comfortable with that approach?

Mr. Grossman: Yes, very much so.

Ms. Blackwell: Ok. So we don't have to determine today who would be writing what paper. But if you're interested in writing a particular paper on one of these topic areas, that would be terrific. Or a particular topic area, that would be great. Then I guess we could go to look at best practices? They could absolutely have a long term or at least 10-year impact on public policy. So that gets us right back in to speaker land.

Well, since we're there, I'll throw out a speaker that I would like to hear from, that I think holds promise for systems change and reform. I started thinking about evaluation

and how adults with disabilities are evaluated. In my mind, when I started thinking about this workshop, I went well beyond just what's being done for people with autism. And I started thinking about the use universal assessment and how that could benefit a state and a person. So interestingly, I talked to the DD director in Washington State yesterday and she was kind enough to send me more information about how the state is using a standardized assessment process. It is beneficiary to it on two levels. One, it helps them to predict cost that they can report to their legislature. But two, it really evens the playing field for the assessment of people with disabilities. And it looks at people with disabilities from a) what can the person do standpoint? It also sort of takes away a lot of subjectivity that might be embedded in the case management. The fact that a case manager is carrying a really heavy caseload and case managers are people

just like the rest of us and think differently. This system that was implemented in Washington State a couple years ago is working. It does incorporate some elements of evaluation systems that are being used elsewhere, but the state tweaked it and is actually using a similar system for other populations, not just people developmental disabilities. They did some edits to it and it's worked out really well. Not just state officials like it, but the legislature likes it. It turns out that people with disabilities and their families really like it. And it just sort of evens the playing field that might not be even in a lot of states. The whole idea of universal assessment, I think holds great promise for the future. That was one that I really am interested in hearing more about because I can see that eventually translating into some sort of national assessment.

Ms. Resnik: This is Denise. Ellen, I think that's an excellent idea and it hits on a lot of areas in terms of cost efficiency, service delivery, and great consistency from state to state. I can see where something like that could play in very nicely to the way that we're talking about.

Ms. Blackwell: Thanks Denise. That was just one my examples because I was really trying to think ahead about what are the sorts of recommendations that we would make. So if we had some sort of recommendation around universal assessment, that could sort of feed into it. That was my thinking.

Ms. Resnik: And that's one of those things crosscutting for all areas, which I really like. And I apologize I need to get in to another meeting, but I will be following up and if you want someone to help you on the adult one-pager, I'm happy to do that. So just let me know.

Ms. Blackwell: Thanks Denise. Other

ideas or thoughts?

Mr. Ne'eman: If we are deciding to do more than just recommendations to the Secretary to HHS and also do recommendation to the Secretary of Education. And I don't actually know if we can do that. Somebody should probably check that. I would be very interested in hearing from somebody from the National Inclusive Education Initiative or from, I believe there's another technical assistance center on inclusive education. There may also be one specifically around inclusive education for students on the spectrum. If we look at the data from the DOE, students on the spectrum are disproportionately segregated. And so I would be very interested in seeing what kinds of practices and systems change policies could be implemented at the national, state and local level to make some progress around promoting school inclusion for students on the spectrum. Particularly given how that's going to lead

into broader community integration possibilities, after people exit the idea infrastructure.

Ms. Blackwell: Yeah, I think that's a great idea, Ari. This is Ellen. In fact, I suggested to Lee earlier today that the 2 of us might want to sit down with Bill East because I am not an expert in education. I did talk to Bill today about some of the project that he knows about that are going on in states. And we did talk about inclusion, and Bill indicated that are some pretty cool models out there that we might be able to hear more about. I think that's a topic that holds a lot of promise. In the school area, another one that came to my mind today is - and Bonnie is not with us so I sort of feel like I'm filling in blanks for her. At CMS, we know that there are States that have used school-based health centers very successfully. In fact, we recently approved a large demonstration under our CHIPRA grants project

to the 2 States of Colorado and New Mexico. Colorado has been doing just really incredible and amazing things with school-based health centers for years. And Colorado and New Mexico have gotten together to propose this project to infuse their school-based health centers with even more rich services that could potentially benefit people with autism and also result in some systems changes. Those two States or Colorado for example, might be ready in November to come in and talk about some of the things that they're doing in that realm. That sort of plays into another thing that was on my mind, which is that of the health homes And again, Bonnie is not here today, but we at CMS have been charged with looking at the new health legislation and ACCA that talks health homes. I actually went through and started looking for a state that had really come up with robust health home program for both children and adults with any chronic condition. These are for sure just at

the very beginning, but I think that's an area that we would certainly like to look at and focus on perhaps, if we can find a State that's really ahead of the game. I have a few ideas, but I really need to do more investigative work because again, the law is so new and these efforts by our States are so new that I'm not sure we have a great example. But we might have a good State example, where a State is planning to go. So that's another thought that I had, very highly supported by our colleagues at HRSA

Ms. Lewis: This is Sharon. Can I ask a framing question? In terms of the overall conversation, my understanding, in terms of purposes and intent here from the service perspective, I thought in part was to talk a lot about human services, education, community based service system opportunities that support people more broadly that are not necessarily primarily focused on health and medical because we do have a lot of that part

of the conversation going on. And maybe I'm off based, if I am tell me, but when I look at the topics that we've talked about in kind of the systems that we may be looking to influence with this conversation. I guess my question is, is it more of that medical model or is it more of the community, education, human services model?

Ms. Blackwell: Sharon, this is Ellen. I think we're really looking at the community, education, services model. When I say health home, you're clearly hear me say health home and not medical home because the kinds of programs that I'm talking about reach well beyond connecting people to physical health services.

Ms. Lewis: I guess in my experience, the school based efforts - in terms of health and wellness - are a broader holistic approach that are not necessarily what we're trying to get at is 1) school & education services that's a very, you know I'm just again by way

of focus, wondering if we're doing a panel on education, I think it should be a panel on education. And if we're going to talk about school-based health services and the role of access to community and health & wellness from a holistic perspective is a different conversation than education access and services? And this is my perspective. Others may feel differently.

Ms. Blackwell: Well I'm definitely not saying that that's the best idea. And I am qualifying my own experience by saying that I'm not an education person and Gail isn't with us today. My thought was that Lee and I could talk to Bill East to get a better handle on what's out there. But if any of the Subcommittee members have ideas, please send them to us, because I think we'd really like to hear more about what's out there.

Ms. Lewis: And I apologize because I am also going to have to run. I've got 4 people standing here who have been patiently waiting.

But I appreciate the conversation and I will put together some additional names and glad to be part of this Services Subcommittee and look forward to moving forward in this conversation. So thanks Lee and Ellen for starting the conversation and establishing the framework in kind of getting off the ground so that we can get this done.

Ms. Blackwell: Thanks, Sharon.

Dr. Daniels: This is Susan and I'll just jump in for a minute to address the issue that Ari brought up about whether we can provide formal recommendations to the Secretary of Education. I believe that this committee being advisory to the Secretary of HHS, but not necessarily to the Secretary of Education that we may not be able to do formal recommendations, but if we're not able to we can certainly can still sent an FYI to the Department of Education. But I'll follow up on that and find out more before our September 13th meeting.

Mr. Ne'eman: So it'll be a distinction, just so I understand, we're talking about the distinction between formally being able to say, 'We recommend to the Secretary of Education this.' Or instead being able to say, 'We believe that this issue is also important and we suggest that the Secretary of Education explore it in this way.' Am I understanding that right?

Dr. Daniels: So if we are able to provide formal recommendations, they would be more of just saying that the full committee of the IACC has found these items of recommendations for the education system and to send them to the Secretary of Education as an informative statement, but if we're not formally advisory to him that we wouldn't be able necessarily advise him. But I'll check on that in the meantime and let you know in September what we can do.

Ms. McKee: Ellen, this is Christine and

I guess since I've listened to ideas for speakers, I'm still flip flopping back and forth between themes versus our topics. And it just beckons back to what the IACC originally did when we first started the Strategic Plan and we had those 4 categories: diagnosis, risk factors, treatment and things kept blending between the different topics and that's why we came up kind of with the, what we did with the Strategic Plan, where we went with, when should I be concerned, or questions - that weren't so - they are siloed, but it's broader than just that individual topic. And I'm wondering, if there's a way for us to change our topics to follow more what we did with the Strategic Plan, to get have a different set up so that - an example would be this inclusive education and you go back to our topics. Well inclusive education, are we really talking about communities? Are we talking about for is it early education? We're skipping around and maybe duplicating

our efforts and it's hard to identify speakers per topic with the set up that we have. And I don't know that just going with our broad based themes - again, we're staying so broad - that I don't know that at the end of the day, we're going to have any real direction from a day's worth of work. I don't know and I don't have any good suggestions other than to say, that I think we need to look at maybe mixing up our topics a little better or coming up with a better framework to move forward.

Dr. Rice: This is Cathy. I feel like there are so many excellent speakers that have been suggested and things that could be covered, but I'm still feeling overwhelmed by not having those sort of guiding - even though we these themes, then it seems to be really big. Thinking of, can we form these themes into questions that would sort of cover the major areas? I think it's a nice suggestion. Or maybe it's not, I don't know. I don't want to keep sort of saying we should start over

because so much good work has been done. But I guess I'm also feeling that stuff without the structure is so umm, you know for each of these themes - so like the speakers that you were just suggesting, Ellen. I guess I'm still not seeing how they quite fit into to theme and how that will end up in terms of a recommendation. So is there kind of a question that could be addressed in terms of - I can't even think of the, I can think of the, oh an identification question about or an identification question that goes across the lifespan, but that services-based - of how do individuals come to understand, how do individuals' families or communities come to understand that an autism spectrum disorder is present or something like that. That's a very poorly worded question, but some sort of question that gets at diagnosis, getting into service systems across the lifespan. And then there's sort of a guiding question that talks about how do you get support services that you

need. I may be going off on a tangent. I'll let other people talk.

Dr. Huang: This is Larke. I'm sorry I had to leave and then I've just come back. I think that - whoever just spoke and the last 2 speakers - what I was trying to get at with my earlier comment was that I thought the strategic plan with those very, kinds of easy-to-understand guiding questions organized a wealth or research. I'm wondering if we need the same kind of thing around the services piece. It could be, what do I need to do or have in place to know that my child has autism? But we should go across the lifespan in terms of at or for a certain developmental stage. What is the system of services and support that need to be in place? And then that gets into, what are those interventions? But are the policies that support the funding for that? I think a critical piece is us not staying siloed. What is that infrastructure that needs to link up the health services and

the education or the education and the employment? I feel like we have discreet topics and discreet systems we're speaking about, but we're not getting at it the way a family marching through the system and through their developmental stages have to organize it. Does that make any sense?

Ms. Blackwell: This is Ellen. Yeah, I'm just looking at the plan itself.

Dr. Huang: I think there are pieces of the plan and again, I'm not really clear in terms of how we make recommendations to the Secretary or even to different Secretaries. And how we stay connected to this Strategic Plan. I think there should be a parallel piece of the services research or the policy research that should accompany some of the basic science research in the plan. I think if we deviate too much from that then I'm not sure where we're going to get the resources or to carry out any recommendations we may have around services pieces.

Mr. Ne'eman: My concern there, once again, is the Services Subcommittee - we definitely do want the Strategic Plan to include services research and we should fight for that and we should advocate for that when the time comes for the strategic plan. But we do not want the only output for the IACC to be recommendations on research. The gap that we currently have - and it's well within our mandate to do this, it just seems like we haven't so far - is that we're not issuing recommendations on policy and everything that we do is through the prism of the strategic plan then we're not going to be fulfilling our obligations to issue recommendations to the Secretary around public policy and systems change.

Dr. Daniels: This is Susan. I just want to clarify for you that you are not in any way bound to follow the Strategic Plan. In this area of the Services Subcommittee you are free to come up with other recommendations

or other products that also can be shared with government officials. So, you don't have to stick to the Strategic Plan. If you wish to stick to the Strategic Plan and try to work through that structure, you're free to do that but you're not required to.

Ms. McKee: Ari, this is Christine. I fully agree with you. When we were talking about the Strategic Plan, my view of it is that we do an entire Strategic Plan on services. That we have something just as robust as the Strategic Plan that addresses research issues to address services and to run with it rather than limiting it to the Strategic Plan. I absolutely agree that the services research has to be a part of the research strategic plan. But I would love to see an equivalent document focusing on services and where we are and where we need to be.

Mr. Ne'eman: I like that idea and apologize if I misunderstood you. I do think

that's a good idea. I guess the one thing I would say then is if we're going to do that, we will need to come up with a process that will let us involve more folks instead of get more work out of more folks and just be provided with the people on the Services Subcommittee. So maybe we want to explore and look at the process that was utilized to write the strategic plan and to bring together panels that could do work around particular topic areas and look at that as the follow up to the workshop. But that's really a great idea to have a services strategic plan. I'm totally on board with that.

Dr. Huang: So I think some of the questions in the strategic plan. If you look at question 5, where can I turn for services? What types of services & support should I seek? Where can I find them? What is my state or local government doing to provide services? What is the cost and how will they be paid? What infrastructure systems need to

be supported, strengthened or built? And I think those are services questions and very much can generate service policy recommendations.

Unannounced Female: Larke, did you just write those down?

Dr. Huang: I'm reading right from the strategic plan. I'm reading on page 29 and 37. They are the parts of the strategic plan that I think are really - really lend themselves to a services strategic plan. And really doing that scenario at different - because the service - the system of care or services is going to change depending on the developmental stage of the individual. So I think that we can't lock into one set of systemly care - that it has to be developmentally appropriate. I think we can back out and say that there are for the key principles that need to be thought of in a services strategic plan. And then I think we can also build on some of the questions and

the road map we did a long time ago to really come up with that kind of services strategic plan.

Dr. Rice: This is Cathy. Some of the questions could be tweaked slightly. I think you've pulled out several that are applicable, but one like which treatments and intervention will help? That is framed in more in particularly a research agenda way. But instead of - will help in terms of? How do I access treatments and interventions? That will help. We're talking more about the how questions here.

Mr. Ne'eman: Is there any value to organizing this by lifespan and looking at some of those questions from the strategic plan - priorities for each place across the lifespan?

Dr. Huang: Well I think in terms of services it probably would have to be because different funding systems fund different kind of services. But I think there are different

developmental stages we could do service scenarios around the different developmental stages.

Ms. Blackwell: This is Ellen. What I'm hearing is that maybe the focus/the outcome for the workshop should be to inform a strategic plan for services. But that still leaves us with, we need to make decisions today about what we're doing with this workshop. That's very important in terms of planning who we get to speak, which we really have to do very, very soon.

Mr. Ne'eman: I think we may need to resolve that our September meeting is when we're going to finalize our speakers schedule because it sounds like there's more discussion that needs to be had over the structure.

Ms. Blackwell: Well, I just need to tell you that giving people 6 weeks notice to come to a meeting is going to mean that we don't get a lot of the speakers that we want to come. Susan, would you agree with that?

Dr. Daniels: Yes, this is Susan. We're at 3:30 right now, which is the time that we were going to end the call. We can continue the call beyond that if we wish. The meeting could change, as it says in the federal register notice so we can continue on. But you know the risk of going into September without any structure or speakers for the meeting is that it will be difficult to get all together before November 8th. As Ellen said, many of your high priority speakers may not be available if we ask them in September. If you decide something on September 13th, it'll probably take us a few days to get an invitation out. But I don't know if you want to continue on and if you feel like you even know enough about the structure to choose any speakers at this time.

From what I've listen to so far of what you've all said we do currently on the schedule that was put together, have areas according to the RFI that could be used to structure the time

of that day. But we also, if you would prefer, we could structure the day around these 3 key themes of systems change, cost effectiveness, and building a theme with systems. And we could substitute those in for those 6 areas or we could do the lifespan areas as themes. It would be just helpful to know you want to do with the day in terms of that structure and then we probably can - it might make it easier for you to choose speakers. I don't know what the group thinks, but if you could discuss that, that would be helpful.

Ms. Blackwell: This is Ellen. I think if we go with the key themes we have the most flexibility, especially in terms of impacting public policy. I think if we're going to write a strategic plan for service we can certainly infuse the lifespan perspective into that, as we did with the other strategic plan. Lee?

Mr. Grossman: I'm here. Well, I'm

feeling nervous just because of the timeframe that we're on, in terms of getting invitations out to people.

Ms. Blackwell: I agree.

Mr. Grossman: And particularly since the November 8th date follows 3 autism conferences that I'm aware of that are happening a week before. I know some of those people that I recommended are going to be at any one of those conferences the week before. I think it's imperative somehow for us to get people at least an indication that they need to save the date. I would think that anybody that we would invite would feel honored to be invited and would do the best of their ability make it to this conference. But, we have to be realistic too, six weeks is not a lot of time for any of these folks. I don't know how to speed that up though, in terms of us getting announcements out. I'm really feeling pressured to do that.

Dr. Daniels: This is Susan. I know

that the committee wanted to have this workshop in November. One other option that you might want to consider, is moving the workshop to spring - changing the date - if you don't feel like you can come up with a structure and some speakers within a timeframe you think you'll get a quality conference because I know that you all care about having something that's going to be meaningful and useful. That would be just one other option that you have in front of you.

Dr. Rice: Along those lines, then we'd have the September and the November times that people had already set aside that this group could actually get together and come up with a structure plan because I think that what people keep coming back to is having a hard time figuring out which structure we should move forward on. And I think we just need to do a little bit more work on what those different structures are like.

Ms. Blackwell: This is Ellen. I guess

I'm concerned that this is the one workshop that the full committee wanted to have this year and I would hate to lose that opportunity to have a 2010 workshop, especially with the focus on services. I just hate to really lose that. We've already got the date. We've got the place. You know Susan's been sending out notes to the committee asking for suggestions and frankly we didn't receive that many. So we do have, Lee and I, spent a lot of time putting together ideas so I kind of hate to lose this big placeholder.

Mr. Grossman: Yeah and, this is Lee, I think what Susan suggested is reasonable, but I really would hate for us to not do this, this year. We've been putting this off, we've been challenged by the leadership of the IACC to get moving on it and we should. And I strongly advocate that we make this date in November happen.

Ms. Blackwell: Does the committee want Lee and I to put together concrete ideas for

speakers under the 3 key theme areas and then have people vote on them? I'm just trying to think of another way sort of resolve who the speakers are going to be.

Mr. Ne'eman: As long as we have a chance to discuss them, via e-mail, and have some input and back & forth on them, I think we trust you and Lee to come up with a first draft.

Ms. Blackwell: Susan, do you have any objections or suggestions to that method of organization?

Dr. Daniels: So my suggestion with that is that we can have discussions via e-mail, however just be aware that you need to copy me and copy Della please.

Ms. Blackwell: I meant that you would send out something to the subcommittee and folks could respond to you, I guess that's how I was envisioning it.

Dr. Daniels: Are you talking to me Ellen?

Ms. Blackwell: Yes.

Dr. Daniels: That I could send something out to the subcommittee?

Ms. Blackwell: Yes and then folks could weigh in on what we send out.

Dr. Daniels: We can do that so Della will probably be doing that in my absence while I'm away.

Ms. Blackwell: Della, would you be willing to help us with that?

Dr. Hann: Sure. I can do that. One question I just have for you though, I guess I was hearing that there were two potential models. One was the model with the themes and the other was the model was structures by age?

Ms. Blackwell: Yes. I'm still a little stuck on that myself, but I guess what I was hearing from Christine was that maybe we would attempt a life course approach for the services strategic plan. Did I get that right or wrong? That we would organize such a strategic plan by lifespan? That's what I

have in my notes.

Dr. Daniels: Meaning that you would have it be the three themes? The systems change, cost effectiveness, and seamless systems?

Ms. Blackwell: For the meeting and I was hearing that the strategic plan would be organized across the lifespan.

Mr. Ne'eman: Yeah, I think that that's what we've been talking about. I don't think the strategic plan for services should be organized by those three themes.

Ms. Blackwell: Yeah, that what I got that the themes for the workshop would be then the three that Susan had put on the memorandum that went out yesterday or today.

Dr. Hann: Ok. Yep, that makes sense. So Ellen, I'm fine with if you and Lee want to craft something and then send it to me and I can send it out to members of the subcommittee for comment. I'm fine with doing that.

Ms. Blackwell: And then could we ask,

also, that the members of the subcommittee, who have not sent ideas or have more ideas after listening to this conversation, send their ideas to Susan or to Della. Excuse me, Susan will be gone for an extended period, to pass along to Lee and me. I think that would probably work. Don't you, Della?

Dr. Hann: Yeah, I think what would be best, Ellen, is after the call today to send a note out to the subcommittee telling them to do that and to have a date by which to do that.

Ms. Blackwell: Ok. Lee, you and I can work together to do that, right?

Mr. Grossman: Yep.

Dr. Huang: Ellen, on this key theme of cost effectiveness, do you mean cost effectiveness or do you mean a financing strategy for services?

Ms. Blackwell: I think what we meant here is, we use the term in medicine a lot, I apologize. In our statute, I would say that

right now in this environment, states are looking for practices' systems and procedures that are both cost effective and quality -that are not the most expensive, but that are ways of finding efficiencies in services delivery that either permit them to provide more services or different services or better services or more services. For example, one very good example of the use cost effectiveness is manage care delivery systems to deliver home and community based services. Now Sharon has left us already, but more of you are probably familiar with the idea of manage care delivery service systems in the context of physical health services. But here at CMS we are starting to see states, including the state of Pennsylvania which has a very unique program that's supposed to serve up to 200 adults with autism, where all of the services have been including physical health services and home and community based services are being delivered through a risk based,

capitated rate. So that would be an example of a service delivery system that's cost effective. Does that help at all, Larke?

Dr. Huang: Yeah, that helps a lot because we really look at that as sort of the financing infrastructure.

Ms. Blackwell: Ok, ok.

Dr. Huang: So now I understand what you mean by cost effectiveness.

Ms. Blackwell: Well I guess from a state's standpoint it could be cost effective to the state. You know what I'm saying?

Dr. Huang: Yeah, and I guess I'm thinking that the Medicaid piece is a big piece of the financing, but especially with health reform now there are going to be - we look at the services in support in a system of care - there will be Medicaid financing, but we also have to look at, with health reform, new sources of funding that will be picked up with new expanded health insurance. But also then what would be state's role. I mean I

think there's different pools of funds now, the state pools, the private insurance and Medicaid. To me, how do you blend all those in a system of care that is really comprehensive across all the supports that are needed?

Ms. Blackwell: Well and when I was talking with Bill East this morning, I said - do you have any samples off hand where you could talk to me about how local education agencies have perhaps worked together to find cost efficiencies or innovative ways to pool their resources? And that's where Bill said - no, I need to think about this more. So when I say cost effective, I guess could almost say cost efficient. You know it's the same sort of idea. Efficiencies that help providers do more with less.

Dr. Huang: And I guess we look at it as what is going to be bought by Medicaid?

Ms. Blackwell: Oh, ok. But there could be things out there in school world, in

education world that I really am not familiar with at all. And I'm not sure Sharon liked my example of the school based health centers because she was seeing that as a medical service being delivered in that system, but I'm sure there are other really good examples - someone mentioned inclusion earlier. I'm sure that we could get a state or a L.E. aid that could talk to us about how they've use the requirement to serve children in the least restrictive environment. Not just as good for the child, but good for the school system and good for the state in terms of its cost effectiveness and quality. I'm sure there are all sorts of examples that could fit under these key themes that I haven't contemplated.

Ms. McKee: Ellen, this is Christine again. If we lose our topics, it kind of throws out our draft agenda for the day.

Ms. Blackwell: Should we keep those topics and overlay the key themes on top of the topics?

Ms. McKee: You know, I don't know. I don't know how to add structure to the same individual who would talk about system reform, cost effectiveness and building seamless systems for each age group or bracket. It kind of does self-impose a life span view on it.

Ms. Blackwell: I think the problem with that Christine is that there's so much overlap. For example, children in the school systems could be served concurrently in the developmental disabilities systems. Then you start to get tangled up and the systems are just on top of each other. Especially when you get transition, then you get to the vocational system starts getting wrapped up with the education system and the person could still be served by the D.D. system. That's where I start to get really confused.

Mr. Ne'eman: And let's not forget some of the systems that we just haven't been talking about at all, like low rehab or even

the independent living centers. There's varying degrees of expertise or it will be around serving adults and children on the spectrum in those systems. That may well be one of the things we need to work to correct.

Ms. Blackwell: But one of the systems we didn't talk about at all is the criminal justice system. One of the suggestions that I had was to bring in a jurisdiction that's done really good work on diversion programs for people with developmental disabilities.

Again, if you start looking at ages, I'd hate to superimpose the criminal justice system on adults or children. I'm not as jazzed to putting ages as I am to leading our topic areas and trying to still work within the context of those and as Lee said earlier, we came up with those because those were the areas that the public identify as first and foremost in its mind.

Mr. Ne'eman: But Ellen, I guess we have to draw a distinction here between these

services strategic plan that we're priming for and the workshop. I agree with you around the workshop - it may not make sense to talk about ages. Around the services strategic plan, I think there's still value to it.

Ms. Blackwell: No, I agree. I'm just talking about the workshop right now and whether or not we should just stick with the key themes or if we should keep our 6 topic areas and try to keep working within those. Are people ok with that? Lee, how do you feel?

Mr. Grossman: I'm going in the direction wherever the committee would go.

Ms. Blackwell: Yeah, I'm kind of there too. I mean you need to tell us what you want us to do. If you want us to leave these topic areas or just go with the key themes. I mean tell us what you want us to do.

Dr. Rice: This is Cathy. I think certainly you guys have put a lot of thought and are feeling more clear about the structure

I think than maybe some of us to who haven't been as involved. I apologize, I know you've done a lot of work and so the concerns I'm raising aren't to diminish that. At this point, I think separating it out by the workshop and having a services strategic plan makes it a lot more clear to me. I would say let's just stay with the themes that you've already developed. What I would suggest is when we meet in person in September we talk about how we - maybe we spend a little of time talking about the structure of the services strategic plan and how we think the workshop can form it.

Ms. Blackwell: Although I have to caution you, by then the workshop agenda will be set.

Dr. Rice: Right, so to me at that point it's not that the workshop has to directly feed into strategic plan, but there may be information. And that'll learn something about adults no matter how we structure it for

the strategic plan. That will help me then think about what kind of discussion or what way we're going to move forward with the strategic plan. So what I'm saying is then, so if we're talking about a lifespan approach or maybe it just would help for sure to think about or just keep in mind that we are going to have the strategic plan. And then as I'm hearing these speakers, I'm going to want to think about, 'this is going to inform this question of the strategic plan' for my own education not that we have to have a report that says that's how it happened.

Ms. Blackwell: Yes, I think that Lee and I can do both at the same time.

Mr. Ne'eman: So are we going to allocate some time at the September to start planning for the strategic plan?

Ms. Blackwell: Yes.

Mr. Grossman: And as far as I'm concerned, I'm very supportive of that as moving forward. I like the fact that we can

part this out and that we're moving - to me that's the logical next step as to start thinking about how we would put together a separate services strategic plan that is so necessary.

Mr. Ne'eman: Lee, I have one additional question. When we talk about a services strategic plan, what we're really - my understanding, and correct me if I'm wrong here, is that what we're really talking about is a services policy strategic plan that services research is going to continue to be represented in the general strategic plan. Is that correct or am I off base on that?

Mr. Grossman: Well, I'll put on my chair's hat and say we'll follow the direction of what the services subcommittee thinks it should be. My preference would be as you described it, that the research component would be part of the research strategic plan and this would be something separate that would deal with the types of policy and

systems change that we need to implement.

Mr. Ne'eman: Well I guess it's another thing for the agenda on the September meeting and maybe in between now and then we can explore what the implications for availability of funding for services research would be for both options.

Ms. Blackwell: Ok. So it sounds like we have plans, right? That we have a plan for the workshop and have a plan to plan a strategic plan. Ok? Ok, so this is good. Lee, you and I will schedule a meeting very soon to talk more about that. We'll be sending out further materials to the subcommittee.

Dr. Daniels: This is Susan. So what we can do here in OARC is revise the agenda to reflect those 3 key themes. We can augment the list, so that the list of potential speakers that you have, that Lee had a few suggestions and if anybody else has suggestions we can add to that list and send

that back out with a request for more suggestions. So Ellen and Lee, if you have things you want to send out, if you can send them to Della and me, we can make sure that subcommittee gets them and can provide you with the feedback you need to work on your draft of the full workshop that includes speakers.

Ms. Blackwell: Ok. That's great. That's what we'll do.

Ms. McKee: I have one more question. This is Christine. As we go down for the workshop, we're designating people to act as speakers. But then those speakers will also be part of panel discussions. Is that what we're anticipating the 45 minutes to be? Are we simply looking at more presentations.

Ms. Blackwell: No we actually thought - Christine that was Lee's idea to have the speakers give a quick presentation and leave a little time for questions from the attendees, the IACC members.

Dr. Daniels: This is Susan. If you have 3 themes throughout the day then we can double the times so we can have those two 45 minute sections added into one theme because we'll have 3 rather 6.

Ms. Blackwell: Well I thought we hadn't totally counted out the idea, Susan, of leaving the ones in there and then superimposing these 3 on top of them.

Dr. Daniels: Oh so you will be discussing each of the 3 themes under each of the others? So adults?

Ms. Blackwell: I think we still have to figure all that out.

Dr. Daniels: Ok, then you guys will need to work.

Ms. Blackwell: And then we need to figure out the background papers too.

Dr. Daniels: Alright.

Ms. Blackwell: Right, Lee?

Mr. Grossman: Oh yeah and all of our callers. I want to thank everybody for

hanging in there past the scheduled time and if anybody that's listening on the phone that's not part of the committee, thank you also for hanging in there with us.

Ms. Blackwell: Yes, we second that here.

Dr. Daniels: Thank you all very much. And just a reminder to keep Della and me informed of any conversations that are going on regarding the services subcommittee, in compliance with the Federal Advisory Committee Act. And thank you so much for all your work on this. We look forward to seeing you again in September. Thank you.