U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

SERVICES SUBCOMMITTEE MEETING

THURSDAY, MARCH 26, 2009

The committee met in Conference Room E of the NIH Neuroscience Center, 6001 Executive Boulevard in Rockville, Maryland, at 1:00 p.m., Ellen Blackwell and Lee Grossman, Co-Chairs, presiding.

PRESENT:

SUSAN DANIELS, Ph.D., Office of Autism Research Coordination, National Institute of Mental Health, and Designated Federal Official

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

LEE GROSSMAN, Autism Society of America

GAILE R. HOULE, Ph.D., U.S. Department of Education

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

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

CHRISTINE M. McKEE, J.D.

PRESENT (continued):

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

AZIK SCHWECHTER, Ph.D., Office of Autism Research Coordination, National Institute of Mental Health

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

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PROCEEDINGS

1:01 p.m.

Ms. Blackwell: Hi, this is Ellen Blackwell. I'm the Co-Chair of the Services Subcommittee of the Interagency Autism Coordinating Committee. I work at the Centers for Medicare and Medicaid Services. I'm also the parent of a 22-year old son with autism.Sitting next to me is my Co-Chair.

Mr. Grossman: I'm Lee Grossman. I'm President and CEO of the Autism Society of America, and I'm a public member of the IACC Committee, and I have a 21-year old son with autism.

Ms. McKee: Christine McKee, I'm a public member of the IACC, and I have a 9-year old daughter with autism.

Dr. Strickland: I'm Bonnie Strickland. I'm representing the Health Resources and Services Administration of the Maternal and Child Health Bureau, and I have a 38-year old son, going on about 16.

Ms. Blackwell: Okay. Do we have anyone on the phone? Okay.

Dr. Daniels: I'm Susan Daniels. I'm the Designated Federal Official for this meeting, and I work in the Office of Autism Research Coordination.

Dr. Schwechter: This is Azik Schwechter from NIMH. I also work in the Office of Autism Research Coordination.

Ms. Blackwell: And, I'm guessing at the moment we do not have any other Committee members on the phone, so I guess that does it for our roll call, welcome, and introductions.

And, for now I guess we'll just table the approval of the minutes from the February 24th meeting, since we don't quite have a quorum yet. I do expect to hear from them. I have a couple of other members joining us a little bit later today.

One of the housekeeping issues I

wanted to take up with the Subcommittee was something that is actually in the unapproved minutes from the last meeting, which is that Subcommittee members were supposed to think about an expert in the services field, or an expert who might participate in a future working group, and I just wanted to check in with folks and see if they had given that any thought.

Christine, you were at the last meeting.

Ms. McKee: I don't have anyone that I would recommend at this point.

Ms. Blackwell: Okay.

Dr. Strickland: Well, I wasn't there, but I read the minutes.

Ms. Blackwell: Okay, thanks, Bonnie.

Dr. Strickland: Well, Grace Williams I thought. She is a parent of two girls with autism, but the reason I'm recommending her is because she has just joined our Professional Association of Maternal and Child Health Services.

Ms. Blackwell: Oh, great. Dr.

Dr. Strickland: And, she is also with Family Voices, so I thought that it might be a nice bridge between the autism-specific consumer community as well as professional organizations and health services, and also being a parent.

There's also Amy Wetherby that I think who is, obviously, a perfect expert.

I know Larke likes David Mandell from the University of Pennsylvania. I actually worked with David on my autism contract at CMS, but I was thinking about Charlie Lakin from the University of Minnesota. Charlie is also working on a number of research initiatives that look at the Direct Services Workforce, which we are going to need to talk about a little bit more in this country. So, those are the folks that I would recommend.

Mr. Grossman: I just got an e-mail from Gail Houle. She's on the phone, but she doesn't have speaking access.

Ms. Blackwell: Azik just left the room, Gail, so my guess is that he knows about this and he maybe is already correcting it.

Mr. Grossman: We'll get to you, Gail, just hang in there.

Ms. Blackwell: Gail is on the phone. She has the wrong caller number.

Dr. Schwechter: She has the wrong caller number.

Ms. Blackwell: Can you send her an email?

Dr. Schwechter: Apparently, she's listening.

Ms. Blackwell: She can probably hear us.

Mr. Grossman: I'll send her an e-mail.

Ms. Blackwell: Gail, as soon

as we get you on the line we can approve the minutes from the February 24th meeting.

Mr. Grossman: A question regarding people on the working group, I have a long list of people that I could recommend. I guess I wanted to, before I just throw out literally 30 names I wanted to hear from the Committee what they thought some of the objectives were with these individuals, so that I could pull that list down somewhat and make it more appropriate.

Ms. Blackwell: I know, Lee, you weren't at the Strategic Planning Subcommittee meeting. I know that you two are not on the Strategic Planning Subcommittee, but there was some discussion at that meeting about convening expert working groups over the summer to follow up on our efforts to refine the Strategic Plan.

So, I think what we were thinking was that possibly that there may be services groups that may be included in that Strategic

Plan Subgroup. So, my guess is that having these people in town, and all of the staff, that we could come up with a revised draft.

So, you have some time.

Ms. McKee: So, how many people were part of the original workshop group? Because we were already -

Ms. Blackwell: From Services? Ms.

McKee: Yes.

Ms. Blackwell: I want to say there were probably about 15-20 people in that room.

Mr. Grossman: No, it was more than 15, there were probably 20 to 25.

Ms. Blackwell: This was, actually, we met last -- the year before last.

Mr. Grossman: Cathy Rice was also saying she's on the phone, hang in there, Cathy.

Ms. McKee: Were any of the individuals suggested here today a part of the workshop?

Ms. Blackwell: Actually, to change it up, you know, I feel like I would want to have a different person than the one that went with me last time. I know that Brenda Myles was there. I would prefer Brenda.

Mr. Grossman: Well, the four top people on my list would be Cathy Pratt, Brenda Myles, Dr. Martha Herbert, and Martha does a lot there. As well as Ed Carr, Dr. Carr.

Dr. Rice: Hello, Ellen and Lee.

Ms. Blackwell: Yes.

Dr. Rice: Hi, this is Cathy Rice. I've been on the phone for about ten minutes.

Ms. Blackwell: Cathy, we can only hear every other word that you are saying. Can you try it again?

Dr. Rice: Is this better?

Ms. Blackwell: Yes.

Dr. Rice: It's real echo-ey.

Ms. Blackwell: Do you want

to try dialing in again? Okay.

Dr. Rice: I've been listening in, and I've just been a non-speaker.

Ms. Blackwell: Okay. Well, since we have Cathy with us, is there anyone who votes to not approve the minutes that were sent out from the February 24, 2009 meeting?

So, we can consider the minutes approved. Thank you.

Cathy, we were just talking about folks that we could invite to the potential expert work group that the larger group has been talking about convening on the services side for possibly over the summer.

So, I wasn't sure if you had anyone in mind, in particular, or do you have thoughts on that?

Dr. Rice: Well, I just heard Lee's recommendations, and I would add Barbara Becker-Cottrill from the West Virginia Autism Training Center.

Ms. Blackwell: Okay.

Dr. Houle: Hi, Ellen, this is Gail.

Ms. Blackwell: Hi, Gail. Dr.

Houle: I just got the speaking access, but I was off for a while. What are you asking for recommendation?

Ms. Blackwell: At our last meeting, we talked a little bit about convening an expert work group, specifically, for this subcommittee, Gail, but, you know, I think where we are now is, the Strategic Planning Subcommittee, and I know you are not a member of that subcommittee, but I was talking about convening experts to look at our next go around on the Strategic Plan over the summer.

So, we had sort of a preliminary conversation a couple weeks ago about, you know, possibly having a subgroup on Services.

So, if you don't have names today, I think that's fine, because the full IACC is going to come back to this issue, possibly even at the May meeting.

Dr. Houle: Okay, sounds good.

Dr. Strickland: So, can I clarify, we are talking about a subgroup of the larger IACC Strategic Planning Group, not just a group that's going on -- Ms. Blackwell: I think right now that's kind of where we are.

Dr. Strickland: Then I would definitely bring in --

(Webinar audio discontinuity, approximately ten seconds missing.)

Ms. Blackwell: Okay. I also should probably revisit our revised agenda today, Gail.

I know you had inquired, we had hoped to have Captain Robert DeMartino with us from the Department of Defense, TRICARE Behavioral Health Division, and, unfortunately, Captain DeMartino was called for jury duty today. So, he is not able to join us, but it does certainly spur a discussion which we can have now or later about future presentations of the Services Subcommittee.

Alison who is also not able to be with us today, has made a suggestion, and I think it's a really great idea, that, you know, even in our regular meetings we've been so taken up with discussion about the Strategic Plan that we really haven't had the same sort of forums that we had in the earlier IACC meetings, and we need these scientific and services presentations in the afternoon.

So, what Alison had originally discussed with me at one point was, having the members of the IACC do a presentation about their agency, and I thought why couldn't we do that in the Services Subcommittee. You know, Bonnie would be, I'm sure, happy to talk about what's going on with autism at HRSA. I'm sure that Larke or David would be happy to talk about what's happening at SAMHSA. I'm always happy to talk about what we are doing at CMS, and I think that might be a great benefit to the public and also to the Subcommittee members.

So, in addition to just having us present, I think something else we could do is expand beyond that, since part of our charge as a Subcommittee, you know, is to improve communications between government agencies, and perhaps the second part of that is to go to other government agencies and bring them in to talk about their services and service issues.

Do you have some ideas about what agencies we might want to have?

Mr. Grossman: Well, certainly, I think it's great to just have somebody from the Administration do that. They set us as a priority, and there are people now that are, not quite yet, but soon will be able to speak more specifically regarding healthcare reform and disability issues.

The Department of Labor has started to work with our group, as well as some other disability organizations on employment issues. So, I think that would be a great type of meeting to have as well.

And, there's also housing issues that you could have HUD there at some point. AHRQ used to be a part of the IACC, and I think that with the comparative effectiveness programs that they've inherited, and autism being a priority for the Administration, that again maybe not now, but in the foreseeable future that would be a good group to bring in as well.

I've been hearing noise about AHRQ wanting to look at autism.

Ms. Blackwell: AHRQ, actually, worked with us a lot on our quality initiative, so I think that's a plan for our future meetings. And I look forward to some great presentations.

Mr. Grossman: Yes, and we

should get DoD here, too.

Ms. Blackwell: Yes, absolutely.

Dr. Strickland: Well, and I think some of the activities that we are doing together, I think the public wants to hear how the government is working together to address these issues, and, certainly, MCH and CDC are working together on the Combating Autism Act, which is pretty much focused on young children, but I think that, you know, we need to start conversations to help us think more about autism in general.

Ms. Blackwell: We had another Subcommittee member join us. I'll let her introduce herself.

Dr. Huang: Hi, I'm Larke Huang. I am in the Office of the Administrator at the Substance Abuse and Mental Health Services Administration.

Ms. Blackwell: We're glad to have her here.

Larke, we were just talking about the structure of our future Subcommittee meetings, and one of the things that Alison Tepper Singer has suggested is that at each meeting we have

(Webinar audio discontinuity, approximately nineteen seconds missing.)

Great. So does anybody want to volunteer for the next Services Subcommittee meeting?

Dr. Strickland: Cathy, are you on? Maybe CDC and MCH could talk about our respective -- I don't know how long we want to take, but, certainly, Learn the Signs, Act Early, and things that we are doing together.

I mean, maybe there's a possibility of doing joint presentations.

Cathy, are you on?

Dr. Rice: Yes, I'm on.

Ms. Blackwell: I think our next meeting is scheduled on Wednesday, April 29th, is that right?

Dr. Daniels: No, that's not officially on the calendar.

Ms. Blackwell: Okay, all right, so we can set our next meeting, so we'll pick a date.

That would be great, thank you, Bonnie.

So, I guess that brings us -- well, do we have any other housekeeping issues, Lee, that you know of?

Mr. Grossman: Well, we could probably finish up the discussion on the working group, the potential names.

Ms. Blackwell: Okay.

Mr. Grossman: So, that people are clear on who and how many and can figure out what perspective to take on that. As I said, I threw out four names quickly.

And again, not being at that branch meeting that convened a few months ago, that's why I couldn't be at the planning subcommittee meeting, but was there any ideas of them wanting to look at new approaches, or moving -- making the next round of the Strategic Plan broader, or just more of a continuation of what we are currently doing? Was there talk around that?

Ms. Blackwell: Well, I guess, I'm the only one here who was at the meeting. I think the discussion was more about setting up a time line for, you know, the Strategic Plan

(Webinar audio discontinuity, approximately six seconds missing.)

-- by January 26th, I believe. So, the Subcommittee was interested in a pretty aggressive schedule, and they even wanted to know what parts of it needed to be updated.

So, as part of that, we talked about either or both town hall meetings and also convening some of those experts to center around the five questions that are in the Strategic Plan, which are, if you'll give me just a second. I have a large mound of stuff here. I'm sure someone here must have a copy of our Strategic Plan. We had the questions, instead of having groups the way we did before around intervention and, you know, the topics -- I think this expert working group would be centered around the questions: when should I be concerned, how can I understand what is happening, what caused this to happen, and can this be prevented, which treatment interventions will help, and last but not least where can I turn to services?

So, there are a couple here, at least two I think, that are really strong on the services piece, which treatment interventions will help and also where can I turn to for services?

I guess when you think about your experts being in that discussion -

(Webinar audio discontinuity approximately one minute missing.)

Mr. Grossman: Personally, I love that idea. Let me say that looking at these six categories, the services are providing services, which is the ultimate goal of all those questions. And, we do research all the time, even if there's a successful result and outcome out of service delivery.

And it's certainly a particular event that I have thought throughout all of this that we need to do more for in terms of developing services, but I think that's a great idea, and I would support that, but I think it's something that the committee has to agree to and see how that fits, and what the wishes of the relevant IACC people are.

Ms. Blackwell: I think maybe that brings us back to our main discussion topic today, which is to talk about the recommendations.

And what I'm talking about is now on the document that says services and support recommendations, and this is a document that Lee and I prepared as sort of a draft updated program.

So, we weren't quite sure -- you know, we wanted to talk a lot more today about what the committee wants to do. At the last meeting, Alison -- oh, I'm just going to let our next Subcommittee member who has joined us introduce herself.

Dr. Johnson: Hi, I'm Jennifer Johnson with the Administration for Children and Families.

Ms. Blackwell: Welcome, Jennifer.

Let me brief you for a second. We were talking about our future activities, and how we think that going forward we'd like to have a presentation at every Services Subcommittee meeting, and starting with our members themselves. So, Bonnie and Cathy Rice from CDC have volunteered to be first at the next meeting, and then we want to expand beyond the members. For example, today we were supposed to have another person present with us. So, we think this is a really good opportunity.

So, we were just getting into our discussion of our -- I don't know what to call it, Lee.

Mr. Grossman: We had a good name or it. It wasn't road maps, it was recommendations.

(Whereupon, at 1:24 p.m., off the record until 1:26 p.m.)

Ms. Blackwell: I think what we had talked about doing was putting together a document that would have, say, three or four recommendations that could be given to the incoming secretary on the services side for things that we could accomplish quickly.

So, we didn't really get very far with this. We wanted to get more of the committee's input. So, this is really, you know, we left a little bit of the road map, we left a little bit of the road map language in here, and we talked a little bit about what came out of our RFI, but we weren't sure exactly what the Subcommittee wanted to do.

So, that's where we left off with this, you know, do we try to draft recommendations for the Secretary? What can the Subcommittee do? So, I do think we addressed one big thing today, which is to start having these regular presentations, bring in folks from the outside to give us some really good information to share with the public.

So, what do we want this to be? That's my question. What can we get done, and can we do it ourselves, or do we need to bring in others to help us, and if we do, how would we do that?

Ms. McKee: I'd like to get rolling on the services issue --

(Webinar audio discontinuity approximately fifteen seconds missing.)

My reaction was, gosh, I wish there was more about services in here. I would rather get rolling on it, and let's come up with some things that we can do short term, so that something starts to happen, so that the public sees that we are working toward something.

I know it's kind of hard to do when you look at the road map, because most of the goals are so big, so broad, that you -- how you take little pieces of it, it's very difficult.

You know, I think to the extent that this group, since we have a lot of experience here, can come up with concrete basics that are measurable and that we can get moving.

Dr. Strickland: I would be in favor of one more level of analysis.

We've got a particular plan, we've got a road map, it's a little outdated, but it's still there, and it was the consensus of many, many people.

Then we've got the RFI. It seems we could cross walk those three things. There must be three or four things that are absolutely common in the Strategic Plan.

And then, look at that list and see what's really doable. I mean, I hear you that we need to identify something that we can actually accomplish, but I agree, I don't want to spend another six months only to find out that the things that people are telling us to do have already been told to us through the Strategic Plan and the road map five years ago and we've not done any of it.

So, I'm not opposed to doing another RFI, but I do think we need to do that one level of analysis to see what have all three of these guides given us? And what of those things seem doable, given the limited resources that everybody has?

Dr. Rice: Yes, I don't know if you can hear me, Cathy Rice, before we do another RFI I guess I still feel that we should have some people to react to, rather than add a general call for information again.

And so, whether it's combining these different instances to this report, or another thing we were discussing was having the work group come up with general topic areas, what kind of objectives need to be proposed in each of those topics, and move the services forward, and then come up with the Strategic Plan services groups and comment on that.

I guess I don't like just having another RFI before that work has been done. Would that add a whole lot?

Ms. Blackwell: I think it's always important to harken back to the law, the Combating Autism Act law, because to some degree it limits what we are expected to do.

I mean, it says we have to write a Strategic Plan. We have to update a summary of advances. I think that for us maybe one of the important ones might be, even for this Subcommittee, monitor Federal activities with respect to the autism spectrum.

You know, I think even by Dave talking about coming into these meetings and talking about what each of our agencies is doing, actually meets that goal in the Combating Autism Act, and that's something that I don't think we've really engaged in, in our larger meetings on that.

So, you know, I think there are certain things that are within our reach. So, you know, another goal that we have as a committee is to make recommendations to the Secretary regarding any appropriate changes to such activities. So, I guess we would first have to talk and to monitor the federal activities, and then to make recommendations to the Secretary regarding those changes.

Dr. Houle: Yes.

Ms. Blackwell: I guess I would think about this in terms of what is our charge. You've already got a Strategic Plan, that's a separate entity.

Mr. Grossman: Well, I think

that I've been fairly consistent on this, I feel that this gives us a lot of latitude. That concept of making recommendations to the Secretary is one of the areas that we should make plans of doing, and for lack of a better term, take advantage of.

The Administration has clearly set autism as one of its highest priorities, in terms of disabilities, and the meetings I've been having with the people in the Administration recently, that there really is, at this point, because of all the priorities and the other issues that they are dealing with, nobody has really taken a lead in the Administration on this. In the foreseeable future nobody will, you know, there's so many vacancies you can just fill the Secretary position.

But, in the meantime I feel that this is a group that is organized, they can do that. We can start providing recommendations, and providing some direction.

I think what Bonnie was saying about this further level of analysis is great. I mean, we have three very, very key documents that have been vetted through many, many people, many bright minds, and we should give it the higher level of analysis just to see exactly what's out there.

My organization has been working on what we've established as our own priorities for public policy, and one of the things that rings through everything that I've seen in the three documents is the fact that somehow we have to be much more engaged in exchange activities, to trade programs that provide life span services. That's something to talk about, but it's another thing to be able to actually make specific recommendations along those lines.

I think, again, I've always felt that autism was just probably a good model for systems change in the public sector in the U.S., because it pretty much encompasses everything, you know, in the disabilities and healthcare arena.

And, that might be an activity that we want to engage in. I don't know. I'm throwing it out to the group. I certainly don't want my particular vent or biases to dominate on this, because it is an incredible undertaking for us to do that. It would be the most beneficial and significant for what we are trying to do here. And I'm sure there's some other things that will come out of these three documents when you take that higher level of knowledge and look at them.

Dr. Huang: Lee, I guess I want to echo that. I think there are three fairly robust documents, I think doing an RFI is a tremendous amount of work, and I think we have a lot of good information there already.

I see this as a real opportune time to do something around services, and I think that all the economic stimulus stuff is out there, it's very services oriented. It's not necessarily conditions-focused, but I would think that this particular subgroup has a good opportunity because, like you are saying, it's a high priority for the new Administration, but there's nobody there crafting what it should look like.

So, what I'm seeing is, if somebody can craft it, somebody else there might review it, say, okay, let's go with it, because we can't staff up, because everybody has got staff problems.

And, I think that when I see this page 9 on the report that you and Lee put together, I think about the roadmap, and when you were asking us as agencies to do presentations on work that might be relevant, you know, I can say from SAMHSA we don't have a focus on autism, but we have a model of a systems change, major grant efforts called "Systems of Care," that has been around since 1993, increasingly funded every year, you know, for children with -- the language is,

"... children with serious emotional disorders."

Now, we get some use with autism in that, but I wouldn't present on that to say this is what we are doing for autism, but to say more that's a model that I think, really, very much fits what's in the roadmap, what's here, what your RFI is saying.

You know, if you look at the RFI, there's different pockets of services in different sectors, but there are also some infrastructure issues, and our system of care thing is an infrastructure building grant, and really assist in the change piece.

So, for example, you can pull from an individual, okay, across different services, so that there's interagency collaboration. You know, people with autism across sectors, so you don't want seven case managers, you know, in each of those sectors.

But, I think that's a model, you know, and I would love to see if this group came up with, well, we want to propose a grant program that might look at a service delivery system, you know, along these kinds of needs. This is what we got from the RFI, community, family support, school services. I would throw employment services in there, providers, and funds to do the infrastructure which is in each one.

And, I think we -- and HRSA has worked with us on systems of care work, education does, they've done a lot of cross agency work. We are doing a transition piece now because those kids are aging out of the system, so we are involving the Department of Labor. But, I think -- I think that might be an umbrella that kind of pulls a lot of this work together, and starts to move it.

You know, I feel that sense of urgency that, you know, by the time we get out of committee all this stuff, you know, and do the Strategic Plan again, which is a tremendous amount of work, they are going to have another nice Strategic Plan on for the research agenda, but to me this -- you know, I would column out of the Strategic Plan those six questions. Set a column up, what is the research that addresses those. The second column to me would be the translational activities, and then the third column would be the services.

And, I think, to me, that might be what this subcommittee has to advocate for in the larger, because I think otherwise we are going to get so caught up -- I mean, we just got I don't know how many articles to review, research articles to review.

Ms. Blackwell: Oh, I know.

Dr. Huang: You know, I mean they are absorbing tremendous amounts of time, you know, very much, and I think the research is important, but if the research doesn't get translated, or if the dollars just go to research that's going to give us findings, and years from now, we are not doing things for people, actually, we are trying to figure out how do I get jobs, how do I plan for the future.

And maybe I'm really out of line on this, because I haven't attended the last meeting, but there is the sense -- I've been on the IACC for two rounds of it now, and I have yet to see how are we improving services, or how are we getting what we know.

Look at the early warning signs, Act Early, it's a real critical services piece, that should be going out.

(Webinar audio discontinuity, approximately twenty seconds missing.)

Ms. Blackwell: I think we need a framework, just the activists, because I think we are not necessarily the big voice on the IACC, which is the research people, we are the services agencies here.

Dr. Daniels: This is Susan Daniels.

I'd like to just interject that

our transcriptionist needs for us to say our names before we speak, so please do that.

Dr. Strickland: What if we don't want to take credit?

Ms. Blackwell: That was Bonnie.

Dr. Johnson: This is Jennifer Johnson with ADD, and, you know, following up on what you were saying about the importance of looking at services and understanding what we are doing related to services, as it relates to the research Strategic Plan, I guess one thing that I'm thinking about is the enormous scope of services, and the notion of services, and how do we get around that and understand what's going on related to services.

Obviously, there's been some work through this Subcommittee to get a sense of what that is, but it seems to me that there needs to be some kind of parameters to what we are talking about when it comes to services, and the kind of information that we are collecting, and gathering, and organizing, around services, because we could be going in so many different directions, and just some of the things that you mentioned. We don't know where kids are appearing in various service systems, so how do we get a handle on that? I don't know how to do that.

Dr. Strickland: I think there are some frameworks out there. As Larke said, there's an infrastructure framework.

Oh, I'm sorry, I'm Bonnie, maybe.

And, even within our separate ways of looking at infrastructure, there is a lot of overlap, like family-driven, or family-centered care, I mean, that's common to every single one of our frameworks, even if they look different.

The other piece is evaluation. I mean, we are right now launching an evaluation of the elements assigned to us through Combating Autism, so is CDC. I think CMS is doing something similar. We could take a look at those evaluation frameworks, and back out of those to see, what are people engaged in anyway? I mean, we've been told to do this by the legislation. We have funds dedicated to evaluating those things. There are service components to those. Ours is almost completely services. So, I think that we might, again, as we know what that list of things that people told us to do, look to see what's already going on that matches up, then we would have, not only what people have told us to do, we would have activities that are underway, and we would have a mechanism for evaluating those things over the next three years that would culminate in a report back to the Secretary, in terms of what we've accomplished, all with existing resources, because resources are a huge issue.

I mean, it took a year and a half, you may not believe it, but that services roadmap took about a year and a half to get it done, by the time we had all of the expert workgroups, and all of the consensus building, and when it turned out, nobody had the resources to really implement it. And, now it's five years old, and now the priorities have changed somewhat, but we don't want to be there five years from now that we've identified things, that we have no resources to implement, and that we have no mechanism for saying when we're done and when we've finished, and how we've done along the way.

So, I feel strongly that we need to look at some of the things that are in place and match them up with what people have told us needs to be done.

Ms. Blackwell: Actually -- I'm sorry, this is Ellen -- it fits very neatly within what the Combating Autism Act says we are supposed to be doing, which is monitoring what's happening in federal agencies. So, maybe that's the first step.

And, that also goes along with

this idea of having us not just talk about our own agency activities, but start bringing in other people to tell us what they are doing as well.

So, that's something we know we can do, which I know I've been very frustrated looking at the roadmap thinking, I know that we can't do this, or this is written in such a way that it's not something that CMS can do. We can't change our statutes, for example. Okay. And, we can't really control under Medicaid what states do. I mean, we can tell them yes or no, but we are really restricted, but we have some other activities that could benefit people with autism, not specifically, but there are pieces of what we do that -- and, you know, we talked a little bit about the Strategic Planning Subcommittee, you know, and talking about identifying agencies. I mean, it's not just autism stuff, it's stuff that could touch people with autism, as you said, Larke.

You know, you guys have all sorts of initiatives underway, but they may not have autism spectrum disorders written on them.

Ms. Blackwell: Go ahead, Cathy.

Dr. Rice: Another thing that we could do, there are a lot of things that are in the comprehensive plans, what's doable, and what's being done, and what's not, related to autism.

(Webinar audio discontinuity, approximately forty seconds.)

Ms. Blackwell: Cathy, this is Ellen. We are only hearing part of what you said.

Mr. Grossman: But, that part that you said was great.

Dr. Rice: The other part was even better.

Ms. Blackwell: Now we can hear you.

Dr. Rice: Okay, is that better?

Ms. Blackwell: Yes, now we can hear you.

Dr. Rice: Okay. I picked up the phone.

It's still echo-ey on this end, but what I was saying is, you know, as the Combating Autism Act, I believe, does ask for each state to have some sort of coordination or plan related to autism, and some states have put together governor's councils or different specific councils related to autism. And, they've put a lot of work into analyzing the services and the needs of people in their state.

And, one of the challenges is finding all of those reports, and getting access to that great work. And, should one of the roles of the IACC Services Subcommittee is to be a distribution point for that information, to say which states have what kind of coordinating committee for autism, what have they produced, and here's a place where you can go and download all the available reports.

That's a concrete service that maybe we could provide as a coordinating agency or group.

Ms. Blackwell: Cathy, this is Ellen.

I mean, the CAA says we are supposed to monitor Federal activities, but as you all know, and as was already said before, Medicaid is a state-based program, so, you know, in terms of how, at least -- and Gail, feel free to chime in, even in terms of how school services work, I think a lot of this really depends on where you are located geographically.

So, it probably isn't a bad idea to look at what's coming out of those state blue ribbon committees. I mean, I see them all the time. In fact, I saw where it was stated, and I can't remember what it was, they just announced today that they've, you know, geared up for a blue ribbon committee. But, that's probably something we could do. We could ask to see Medicaid agencies or the state development on disabilities agencies to what is now, you know, if they know what state efforts are underway or have been completed.

Dr. Rice: Yes.

Ms. Blackwell: Maybe the National Association of State Development on Disabilities directors would be willing to work with us.

Mr. Grossman: Well, yes, and, well, I believe that they would be.

The other group that's very interested, and have already started to organize teams, is the National Association of State Administrators in Special Ed.

And, we've begun to organize state teams around education, and there are 38 right now that have met the last two years, at a conference, and we are going to be working with NASDSE on that a little bit further.

But, there's just one example of the way that groups are wanting to come together around autism, because they are just inundated and overwhelmed by it, don't know what to do, they all understand and realize it's a growing problem.

And, I think that we could show -- my point here is that there's not a shortage of people out there that are willing to work on it, and help, and get involved in it. I think in terms of getting data and finding out what is going on, on local levels, I mean, all of them will have us managing the amount of information that we'll be getting in, because people are wanting and willing to share this, because they want -- you know, they want some action to happen. And, it's up to us now, I think, to take that information and to make it happen.

I think in the meantime, though, going back to what Bonnie was saying, that we should look at this, and give people a framework of what it is that would be most useful to make whatever changes or whatever has to happen on the federal level, for the federal side to be much more responsive at the state level.

I gave a talk three weeks ago to 200 school administrators, and the title of my talk was, "Using Autism As a Model for Systems Change," in their state. And, you know, it was the first time I did that in front of that type of a group, and I didn't know what type of -- I was pushing the envelope, you know, here's autism, you know, we can do these certain things, and we should make them happen.

And, I really didn't know what kind of feedback I was going to get. I expected a lot of push back, and what I got, surprisingly, was a total agreement and acceptance from people wanting to get behind this.

And, it was mainly because they

see it as a problem that they can't solve, and they are looking for help, and that's the type of leadership I think that the IACC can take, and should take, in terms of making suggestions to the Secretary to make these changes, actually, occur.

Ms. Blackwell: So, what I'm hearing is two things. One, that we can take steps, and we should take steps, to put together some sort of document that summarizes what activities are taking place at the federal level, that either are or may be impacting children, youth and adults with autism spectrum disorders. And secondarily, perhaps, try to start collecting information from states about state-level activities.

Dr. Houle: Ellen?

Ms. Blackwell: Yes, go ahead, Gail.

Dr. Houle: Yes, this is Gail.

We can do that through, as Lee mentioned, the NASDSE, which is the National

Association of State Directors for Special Ed, and we provide them with some funding for what we call the "Partnerships Project," and to run communities of practice, and they've started one around autism.

So, we can -- I do believe that they'd be amenable to working with us to get some information.

Ms. Blackwell: On the state level, Gail?

Dr. Houle: Pardon?

Ms. Blackwell: Is that on the state level, Gail?

Dr. Houle: It's an association of all the state directors of special ed.

One thing that we can't do, but we can work through organizations, is that we, as the Federal Department of Education, I cannot go out and kind of survey or provide additional questions to states, because of the paperwork burden.

Ms. Blackwell: That's

correct, we cannot.

Dr. Houle: So, it's like I could not send out a survey to every state and ask them so many questions about autism, because all that, believe or not, and to people who may be listening who are inside the federal government, is highly regulated so that we have to work through our grantees to do that. And, I think that we have in place the financial assistance to some grantees, such as NASDSE, to be able to work on our behalf.

Ms. Blackwell: Well, would it be -- you know, I think it's doable, and I think it would be great if we can start with these federal collection and dissemination efforts. That seems like something we can, actually, accomplish, that would be very helpful.

Dr. Houle: Yes.

Ms. Blackwell: On the state side, maybe what we could do is, you know, and I'm going to confuse everyone, because the

NASDDDS is the name of -- it sounds like the other name, okay, is the State Directors of Developmental Disabilities Services.

Yes, thank you.

So, you know, we could also have someone from NASDDDS come and talk to us.

Dr. Houle: Right.

Ms. Blackwell: They can talk to us about what's happening on the state level, you know, because they represent the state developmental disabilities directors, who are in charge of these systems, and maybe the same thing could happen on the school side, it sounds like.

Dr. Houle: Yes.

Ms. Blackwell: So -- Dr.

Strickland: And, on the health side, because we have a center with the American -- with the Association of Maternal Children Programs that looks on that.

Ms. Blackwell: I'm sorry, that was Bonnie.

Dr. Strickland: Are you saying for the overall IACC or just for us?

Ms. Blackwell: No, I'm saying just for us, I mean, because it seems like things are kind of -- I mean, I don't want to criticize our larger group, but it does seem like it's -- you know, we spend so much time talking about the Strategic Plan, it seems like, you know, as I said earlier, we lost our ability to have all these great presentations in the afternoon.

So, you know, we as this group, and we don't really do that, Bonnie, we've been spending a lot of time talking about the Strategic Plan.

Dr. Strickland: Do you see importance to doing that, I mean, overall?

Ms. Blackwell: Oh, I do think it is. In fact, I think it's very important, I do.

So, what if we start here, you know, and get somewhere, and then when we've

-- you know, let's say we have an outstanding presentation, in fact, one of the presentations I want to suggest to the larger IACC, and Lee and I have talked about this already, is to start a discussion on the methodology, and the techniques, and the types of interventions that are behind the term, applying behavioral, and so that's something that I think the larger group would be really interested in, and I'll take it up with all of us in May, you know, then we can vote, and we could have that presentation, I think it would be great.

But, you know, to start with our federal efforts I think is laudable.

Dr. Strickland: Yes.

Ms. Blackwell: And then, once we get something together, that could, actually, be the basis of the recommendations, that where are the weaknesses and gaps, and what's going on at the federal level, because I don't think we really know.

So, what should Lee and I do? Should we put together sort of a template to, you know, start to query federal agencies about what their efforts look like? I mean, we could send that out. Co-Chairs of the services committee.

Dr. Strickland: This is Bonnie.

I think that's a great idea, and I would also -- if it's possible to organize it by life span, because I think we all talk about how important the transition and adulthood piece of this is, and yet, Combating Autism is focused pretty much on the early side.

So, I think if -- and we could do this together, I don't think the two of you should do all of this, but as we report what we are doing, try to think about where those efforts are on the life span, so that we can begin to look, not only at gaps in the kinds of services that aren't there, but the age groups where they do or don't occur.

Ms. Blackwell: In my work at CMS -- this is Ellen -- I started to divide them into three groups, children, transitioning youth, and adults.

Dr. Strickland: Good.

Ms. Blackwell: Okay, so is everybody okay with those three groups? I mean, I don't normally put the word transitioning before youth, because there are transitions in people's lives throughout the life span, so I usually just say children, youth and adults, but to me those are the three groups, because -- and I would also harken folks who are listening back to a presentation that we did have before the full IACC in November, and I think some folks heard it, and some didn't, who are here today, but I put together a presentation on services for people with autism throughout their lifetime, and then we brought in other stakeholders to talk to us about services.

So, that's really the first time

in a long time that the IACC has had any opportunity to hear about services.

Ms. McKee: I think we are on the agenda for the next meeting -- this is Christine McKee, sorry -- as a follow-up to Paula's speech last time, or during the public comment section, about augmentative communication.

I contacted Della to see if we could get on the IACC agenda, to have a presentation on a specific issue that deals, specifically, with services, to see if we could get some more attention drawn to this.

And, these are the small things that I think that we can start to chip away at. You know, we keep looking broad spectrum, and, you know, services across the states. Again, that's so broad, it's hard to choose what you are going to do with it.

But, something like the augmentative communication issue, another hot item for me is inclusion, sorry, Gail, within the educational system, and how that's really working.

So, I think that there are these narrow issues that we can bring to the whole IACC, too.

Ms. Blackwell: And, maybe what we could do is also do better querying of our agencies. We could try to somehow bring in these categories that the public identified as being of high priority, because we have what the first RFI gave us, we know that the top issues are adults, community, family support, school services, providers and infrastructure. We know what the secondary issues are. I mean, so that way we could use the public comments to inform our queries to the other agencies, and also, you know, give them our mission and vision statement.

I think you are right, I think that would be a great idea, and it would probably help the incoming Administration in terms of trying to figure out what is actually happening in all of these gigantic agencies that either touches directly on people with autism, or could touch on people with autism.

Mr. Grossman: This is Lee, and just to expand a little bit on that. I guess I would want to get some clarity from the committee, too, in terms of what other outreach we should be doing.

For example, we are right now working with AMCHP and the two NASD's organizations, to the mission. And, there's great information in there, in terms of that type of feedback that we need, that the federal government needs, of what is actually being delivered in the community, and the struggles and successes that they are experiencing.

Should we also be reaching out to them at this time? And, you know, with that said, you can also include the pediatricians, any of the primary care providers would be another good group to bring in.

Anyway, I'm just kind of throwing that out for a suggestion, because I don't want to -- for me, personally, I don't want to jump ahead of what we are trying to do here, but I don't also want to bite off too much more than we can chew.

Dr. Johnson: This is Jennifer Johnson, and I was going to talk a little bit about different lenses in looking at services, and the kind of information that we could collect, and not that we can, necessarily, get to some of the groups that you are specifically identifying, but from our grantee's perspective I think we can look at it through different ways. One is way through a systems change and services perspective, because I think we could get information on what they are doing specific to systems change issues, and how it relates to services. But also, from a direct services perspective, and querying them in terms of what direct services they are offering.

Most of this will be funded by other state and federal agencies, and maybe that's a part of what we asking, is how are these, you know, services being supported, so we get a sense of, perhaps, the blending that's occurring out there in the service delivery, because they are able to bring a number of systems together, in order to provide services.

So, that may, again, offer a different way of looking at this, and I go back to how broad can and should we be in this kind of process. I think the categories that are identified on page nine are a good start. We probably want to add early childhood, because I do not see that, and also the youth, and we use youth and young adults as sort of an age span coming from early childhood into adulthood.

But, you know, there are issues that cut across the age span, and I think what's listed here do address issues that would cut across the age span, so maybe just adding those other items would be helpful to this list that's on page nine, but I think we just need to stay mindful of the parameters, I'll go back to that, for this process, and maybe going to the organizations that you mentioned as a next step in the process.

Mr. Grossman: And, the ones that you served, we've already started talking with the DD Council, because they want to be a part of this as well.

Dr. Johnson: Yes.

Dr. Johnson: And, we started collecting information on what our programs are doing, because we are getting queries from the Administration on other areas that they are interested in. So, we are waiting for the questions to come in on autism, and what we are doing related to that.

So, we've started that process already, and so we can do it fairly easily.

Ms. Blackwell: I would

agree. This is Ellen.

We, for the most part, know what states have particular waivers to serve mostly children with autism. But, what we don't know is, to me, the bigger pool, and as you said, Bonnie, I think Bonnie or Larke, one of you said, we can't -- or, Cathy, I guess it was you, we can only ask -- or, Gail, I'm sorry, certain questions.

But, we know what states have, home and community-based waivers. What we don't know is how many people with autism are being served in these very large waivers, for example, California, 90,000 people, we know what services are in the waiver, but we don't monitor, you know, at the federal level, you know, how many people with autism are in the waiver.

So, the state might know.

Dr. Houle: This is Gail.

We have those large data numbers for education, and so, we can get a pretty good picture when we fit together with some of the qualitative information that we get from our grantees, and from our partnership projects. So, we are not limited, probably, as some other agencies are, because we do collect a lot of quantitative data, less in the qualitative area.

Dr. Rice: And, this is Cathy.

I would just add that the suggestion I was making was, I guess, a little bit even more concrete, stepping back of not collecting new information, which doesn't mean we shouldn't do that, but let's just see what these governors' councils and blue ribbon panels have already put together and have them in one place to serve as a resource for both this committee and other states.

So, that's kind of more of a simpler activity than what people have been asking, because as Gail mentioned, certainly, we do have limits in collecting new information from individuals without lots of layer of approval, unfortunately.

Dr. Strickland: Gail, this is Bonnie.

On your annual report, do you have a way of looking at the age at which children enter early intervention, children with autism into early intervention?

Dr. Houle: We have a way to look at the age ranges of children receiving services under the category of autism, and it depends on, for early intervention the states have the option of reporting either by specifically identified categories under the federal law or under the more generic term, developmental delay.

We have some studies that have taken samples of the early intervention population, and I may be able to go and find some breakouts there, and I am sure that they are more by needs of service category than the child history, like speech and language impaired, children with physical impairments, cognitive impairments.

So, for the really young children, we don't ask them to provide the data by the 12 idea categories, one of which is autism. And, part of that is really at the request of practitioner states, because for many of the idea categories they felt like they didn't have excellent diagnostic tools, but they still needed services under more functional categories of developmental delay, such as speech and language delay.

Ms. McKee: Yes, this is Christine, I would caution a little bit about the numbers at the early stages. I know my daughter stayed off the radar until she was five, just because of the services that were offered. I come from the Midwest, and we had our home program, and a lot of parents chose, they just hire a shadow and put their children into regular education, and they receive no services from the Government that would pick them up as a number until well into kindergarten age.

I wasn't real -- that's a very good point, and I agree with you, entirely, I was just wondering with all the current emphasis on early like AAP now has of -- well, almost a standard of autism-specific screening at 18 and 21 months, Learn The Signs, Act Early Campaign from CDC, and yet, I don't think we have a way of telling whether those children who do make it to early intervention with a diagnosis of autism are getting there any earlier than -- I mean, the thing we laugh about a lot is kids who, with a diagnosis of autism, never get early intervention, because they are not identified until they are at school age.

So, I was hoping that -- I was sort of hoping beyond hope, because I kind of thought, Gail, what you said was true, that we don't really have a mechanism for determining whether those kids who do get to early intervention are getting there earlier as a result of these national initiatives.

Dr. Houle: Well, yes, I think we'd have to -- we'd have to look to IEF, which is now our research arm, to do sampling of children entering the early intervention program.

Dr. Strickland: That wouldn't come out of -- you couldn't get that from NEILS, could you?

Dr. Houle: NEILS is the study I was referring to that was more functionally identified as how many children needing speech and language services, needing services for cognitive delays. So, it was not specific to, for example, you wouldn't have a child that had to be diagnosed as learning disabled to work, those types of categories, necessarily, to be sampled in the NEILS services.

So, it's question that has two sides to the answer, in terms of diagnosis, and in the past it's been developmental delay to allow as many children to receive services as possible, and not excluding, and not saying that you are not -- you can't qualify for services unless you have a certain categorical label. So, it's a more functional approach. If you need speech and language therapy, if you need physical therapy, then you would establish there was either in some states a high risk of developing a delay, or in all states a delay does determine eligibility.

Dr. Johnson: Bonnie, I think -- this is Jennifer -- the questions that you are asking, though, in terms of identification, are things like Learn the Signs, Act Early, working, and helping to identify children earlier on.

What we're learning from the states is that even if those things are -- we don't know that yet, but if those kinds of campaigns are working there's still a service issue, in terms of the assessment process.

A lot of our university centers offer evaluation services. They've been able to do that either through federal funding or state funding, but they have tremendous waiting lists for the evaluation services.

And so, that, obviously, is a significant -- creates a significant delay in that process of getting into the service system.

But, I think that is an important area to look at, when we are talking about services.

Dr. Strickland: Yes, reducing that time.

Dr. Johnson: And then also, related to the Learn The Signs, Act Early, for getting that message out there that we need to know what the signs are, there needs to be a service component related to the pediatricians that are going to be seeing the family, and to maybe raising their concerns to them, but they may not know, you know, if your family is coming he may not have the knowledge, or the experience, or the information about autism.

So, there's another whole service component to that, and what's going on around that.

So, that's what I had to say.

Ms. Blackwell: I think we've made a lot of progress, I'm sorry, this is Ellen, on what we are going to do next.

So, it sounds like Lee and I should develop some sort of a letter or communication. We, obviously, know where to start with the agencies that are part of the IACC. So, if folks have suggestions about agencies that we should talk to, I think that would be appreciated. I'm not saying come up with them today, but Lee and I can try to put together a list and send it out, and then maybe you could let us know if we missed anyone.

Mr. Grossman: I think we should probably run it back to the Subcommittee first.

Ms. Blackwell: Okay. We'll try to put together a letter, and then try to put together a questions letter, okay, and so we know what our presentation is going to be at our next meeting, great. So, are we through discussing the recommendations for now, because I think what we are going to -- the direction we are going in is more to do an assessment of what's happening at the federal level, and maybe what's happening at the state level, and then later on figuring out where the gaps are, and one of the recommendations could be from a systems perspective.

Dr. Johnson: Questions on the services, but you and Lee would be working on in terms of the federal agencies that would provide information.

I'm just looking at, on page six of the recommendations document, in that tier one, that's a five there, and Q1 being things like healthcare incentives, as far as I know, represented here on the Subcommittee or on the IACC, you know, for ACF it's ADD that's represent ACF, and those kinds of programs.

But, I have a feeling that if we went -- were to query those agencies it's probably important to know what they are doing, but would they be able to respond in a way that we want them to.

So, I'm just asking you all, would you want us to be thinking that broadly, or in a more targeted way?

Ms. Blackwell: I think in terms of who we ask -- the question goes more to what are we asking for.

Dr. Johnson: Right, in a way that somebody is going to understand it.

Ms. Blackwell: I think we have to think about that.

Mr. Grossman: We'll have to think about it. I think there's been suggestions that have been brought up in the prior IACC Services Subcommittee about doing such surveys to find out where the federal agencies are at this point, maybe just giving them that would be invaluable, and those that can answer the follow-up questions, what do you think the future needs will be, and what would you like to be doing.

Ms. Blackwell: That's really hard.

Mr. Grossman: Right. I think the first question needs to be what are you doing, and, actually, maybe, Jennifer, if we had to look at what they say before we know what the right questions are to ask, I mean --

Mr. Grossman: Yes, we need to just find out where they are.

Dr. Johnson: Right. And, we could certainly facilitate this information from agencies that we might be working closely with, that may receive this and wonder how they are supposed to respond.

Ms. Blackwell: Right. Okay. Dr.

Huang: Another thing on that query to federal agencies, might be suggestions that you were talking earlier about partners, or partnering, they all have different partnership groups that could focus on them or not. There might be relevant partnership groups.

Ms. Blackwell: Okay, so ask who their stakeholder groups might be.

Dr. Huang: Yes, or whether there are national associations.

Ms. Blackwell: At CMS we just call them the associations. You know, we all have -- but you are absolutely right, Larke, we all know who these groups are that are really interested in what we do, but, I guess, that's part two.

Dr. Huang: Okay. Well, this will be real exciting to have great presentations. It will be good.

Dr. Strickland: So, Cathy, you'll have to -- you and I will have to get together to think about how we want to do this.

Ms. McKee: Okay, that sounds good. How much time do we plan on, what amount of time, do we get an hour?

Dr. Strickland: Yes, that's what I was -- I was thinking an hour anyway, just because I think there are things that are specific to CDC, some that are specific to MCH, and the things that I think we would want to emphasize are the partnership pieces that we are working on, at least between the two of us, and, actually, probably more than just us.

Do you think an hour, Cathy?

Dr. Rice: Yes, I think with time for questions included in that hour, that should be good.

Ms. Blackwell: Okay, so we can take a break or we can keep going. What would people like to do? We do have a couple -- we have a few more things to talk about. Not too many.

Should we take a quick break?

Mr. Grossman: Sure.

Ms. Blackwell: All right. So, we'll take like a ten-minute break, and then we'll come back, there's not too much left, but we have a few things.

Ms. McKee: I'm going to have to leave a little early.

Ms. Blackwell: Shall we just keep going?

Ms. McKee: Yes.

Ms. Blackwell: All right, we can keep going, we can get through the rest of this pretty quickly.

Lee, I was going to let you talk about your suggestions for the town hall meeting --

Mr. Grossman: Sure.

Ms. Blackwell: -- because I think you meant to take that up with the larger committee in May.

Mr. Grossman: Right. It's a good place to bring it up.

My time at the May meeting is going to be limited, I'm going to have to leave early that day.

But, yes, the suggestion is to

have a town hall meeting to get feedback, and the suggestions that we've always thrown out has been on the table for a long time. And, to have it at the July ASA conference, there will be anywhere from 1,500 to 2,000 people there, not to say that there will be 1,500 to 2,000 people at the town hall meeting. The conference is, actually, the 23rd, 24th and 25th, and it's outside of Chicago.

But, and I'm not sure if there will be a number of people that will just come in just for the town hall meeting, but there certainly is an engaged and invigorated audience there already that want to be involved in this process, have their voices heard. And, I think it would be a great opportunity to get feedback on the current Strategic Plan, the entire Strategic Plan, and from a very diverse group, because we will have researchers and scientists there, we will have medical professionals there, and we will have service providers, Federal agencies. We are inviting people from the Administration, and, obviously, there will be family members, as well as a number of people on the spectrum there.

We, actually, get a large turnout from people on the spectrum. So, it's very diverse, and, certainly, there's a lot of interest in our community to have these opportunities to be heard.

Ms. Blackwell: I guess one of my questions is, and this came up at the Strategic Planning Subcommittee meeting, but there was a lot of interest for doing town hall presentations, or town hall interface with the public, so was this the envisionment of the town hall meeting for the Services Subcommittee or for the larger IACC, because there was some discussion at that meeting about having IACC, full IACC town hall meetings. I wasn't able to articulate your voices.

Mr. Grossman: Well, I mean,

when I first put this out it was for the Services Subcommittee, kind of as a follow-up response to the RFI that we issued. But, if -- I think that whatever type of town hall meeting that we do, it will probably run the same course as the other town hall meetings that have occurred, and we did one in Sacramento for the IACC last year -- yes, it was last year, in 2008. The questions are diverse, and it's a very diverse group, and they are going to be across the board. I think the majority of the questions will be service related anyway, certainly, the ones that are coming from service providers and family members, but I think now that it was talked about in the Strategic Planning Subcommittee as follow-up that maybe we should have it broad.

Ms. Blackwell: So, maybe you'll just take it up with the full committee?

Mr. Grossman: Yes, I mean,

unless this committee feels like we really need one specifically on services.

I think when you get into a town hall situation it's hard to limit, you are opening it up to everybody in the audience, it's hard to limit the discussion anyway. So, you might as well take advantage of the fact that we'll just talk about the Strategic Plan, and get feedback on that.

And, we can pose some questions in the beginning, and I think that it could be -- I'm assuming it's going to be, because it is an IACC activity, that it's going to be in the Federal Register, and we can pose questions in there, what we would like to get feedback on.

Ms. Blackwell: I think what you might want to do before the ASA is identify a date and a time.

Mr. Grossman: Yes.

Ms. Blackwell: And then, maybe talk with Susan about, you know, how to work with NIMH to get some sort of cooperation between either the full committee or the subcommittee.

Mr. Grossman: Yes, we can do that. We have three days to play with, and I'll have it on the Thursday or Friday, which are the busier days, and I would think that there would be a few hundred people at a minimum that turn out, or something like that.

Ms. Blackwell: Susan, do you know how people -- how would we figure out way to go?

Dr. Daniels: So, this is Susan Daniels. My recommendation would be at May 4th that you propose maybe two different options, whether the committee would like to use your offer to either have a services-related town hall meeting or something related to the overall Strategic Plan, and let them decide -- show them two different options of how they could use that time and have them decide. There's an option that we could have a separate town hall meeting related to the

Strategic Plan, and if we are going to use your town hall meeting time slot we could bring IACC members to that meeting.

Ms. Blackwell: Thank you, Susan. Great.

So, another way, now it's a great way of bringing, you know, the public opinion, and we appreciate it, so we appreciate your offer, Lee.

Mr. Grossman: Well, and I also think that whatever suggestions other people may have for venue, please bring them up.

I mean, one of the things that we continue to hear is from people that they wish that it would be more open. For whatever reason, and there's many reasons, you know, many reasons in the comments we receive, people don't believe that the IACC process is open enough. And, I think that doing town hall meetings, and not only at our conference, but elsewhere, would really help in making people feel engaged and get more support behind them.

I don't know all the logistics that are involved. We do town hall meetings, we do quite a number of town hall meetings a year, and for us they are easy, but we don't have to put it in the Federal Registry, and we don't have to follow the Federal rules. So, for us it's very easy.

So, I do understand that there are other limitations by the fact that we're a FACA committee.

Ms. Blackwell: One -- this is Ellen -- one thing that I want to address, and I brought this up in the larger meetings, Health and Human Services does have ten regional offices across the United States. In fact, most of those offices are taken up by Medicaid and Medicare folks, and they are all linked electronically. So, it's easy to link up a few of them, it's much harder to link up all of them, because there has to be an actual body or bodies on the other end to coordinate and get people in, they are all in separate buildings. But, there is the possibility of having town hall meetings that are hooked up to each other in different parts of the United States, where everyone can talk to each other at the same time, and see each other at the same time. So, that's another possibility as we move forward, to try to assure that people can always participate.

Dr. Daniels: This is Susan Daniels.

I was just going to say that if the Services Subcommittee feels like you might want to use that town hall time for your own purposes, that maybe you could talk about what you'd like to get out of a discussion, and bring that up on May 4th as well, as to what type of product you'd like to get, because it could be an open-ended discussion where people just talk about whatever is on their mind, or it could be a little bit structured and you could try to get specific types of feedback that will help you in some of your activities.

Mr. Grossman: And, since we are meeting again in April, April 29th.

Ms. Blackwell: May 4th. Dr.

Strickland: Oh, right --

Mr. Grossman: For a Services Subcommittee call.

Ms. Blackwell: Oh, no, we don't have --

Mr. Grossman: Okay, because I also found that on my calendar. I was going to suggest that we can then figure out what topics, collectively, come up with topics that we would present to the full IACC, but I'll just work on it.

Ms. Blackwell: Great.

This is Ellen, and I wanted to mention that we had a briefing this week with a very nice lady, her name is Laura Ginsburg, from the Department of Labor. And, in everyone's packet I think you'll find a copy of a brochure that the Department of Labor has, and I thought it was really interesting, and we haven't talked a lot about Labor, but I have heard quite a bit about this program.

If you look at the CMS web site, you'll see that we are pretty heavily invested in trying to sustain activities related to supporting the Direct Services Workforce, which is a bit of weak link when it comes to people with autism spectrum disorders in particular.

So, this is an apprenticeship program that Labor runs, and there's a sub program called "Direct Support Specialists," and the requirements for that are also in your packet. I just got them last night, and I just thought that folks might like to look through them.

This is a program that's designed for employers, and Laura said it cost a couple thousand dollars to have a person be certified through the Department of Labor, and it is about 2,000 hours for most of these apprenticeships, but I thought it was really interesting, and I've been thinking, in fact, I have asked them whether or not it would be worth talking about maybe doing a sub specialty in autism. So, that was something that we talked about, but I thought that the committee just might be interested in seeing it.

They also -- the Department of Labor also received a good deal of money, through the ARRA, American Recovery and Reinvestment Act of 2009, specifically, if you go to their web site you'll see a program called, "Competitive Grants for Worker Training and Placement in High Growth and Emerging Industry Sectors." A half million dollars of this $750 million allotment is for green jobs, but the other $250,000 is given to projects that prepare workers for careers in the healthcare sector, and that could certainly be, you know, helping the Direct

Service Workforce prepare to work for people with autism.

So, I just thought that was kind of interesting, and I wanted to bring it before the committee.

Susan was also kind enough to send out Kathy Reddington's report, which she just sent me the other day. This is the program that we heard about in November, Cathy is head of the project in the State of Connecticut, actually, a state-funded project to help high functioning people with autism or Asperger's Syndrome get jobs in the community. So, this is the evaluation report that the Lewin Group prepared for them, and I thought Cathy did such a great job for us in the follow-up report. So, you know, take a look at it, it's very interesting.

This is a population that in Medicaid, typically, is not served because of our institutional level of care requirements. So, you know, they are expecting they may not even be eligible for Medicaid.

So, the state has done a great job, this is a very unusual program, and I thought people might be interested in the follow-up.

And, since we don't have a person with us from NIH today, other than Susan, I will mention that NIH just issued a grant solicitation specific to autism. It is RFA MH09171, 172 and 173. One of these, specifically, MH09173, is aimed at services research, which is just terrific. So, for the folks on the phone, you may want to go to the NIH web site and take a look at this one, you know, it's certainly very exciting to all of us, I think, on the Services Subcommittee, to see that NIH followed through. Many of these initiatives are coming straight out of our Strategic Plan, so how wonderful to see our hard work coming to life here at NIH.

Dr. Daniels: This is Susan Daniels.

This week, we also released a $60 million RFA on the heterogeneity of ASD that is very much focused on the objectives of the Strategic Plan, so you should all be very proud of that.

And, if you would like to see the press release for that action, it's on the nih.gov web site. It was released on, like, March 1 -- I'm sorry, March 24th.

So, that's all I have.

Ms. Blackwell: Which institute released that?

Dr. Daniels: This is a trans-NIH initiative with five different institutes, including Mental Health, all the same institutes that are on the IACC.

Ms. Blackwell: Okay. That's great.

So, why don't we just go around the room and give us an update of any activities, anything exciting happening in our agencies. We have funding through ARRA that is taking up a lot of time and action in personnel right now.

So, Bonnie, do you want to start, since you are sitting in the chair?

Dr. Strickland: Sure. We don't have anything specific to ARRA around autism, thank goodness, but we do have what are substantial efforts for our size organization, specifically, through Combating Autism Act.

I've already reported to this committee on the major initiatives, but they have to do with expanding and creating new training activities through our Lend organizations, and right now they are supported at $5.6 million, specifically, from Combating Autism, and we expect in '09 that there will be a minimum of $2 million additional dollars dedicated to the support and expansion of new and expanding Lend activities.

The same holds true for research. We are currently funding $6 million in research related to autism, $4 million around the physical aspects of autism, and an additional $2 million around cognitive social and behavioral aspects of autism, and these are the activities that we are right now trying to cross walk with the research activities identified through the IACC Strategic Plan.

We expect $2 million additional dollars for research in 2009 as well.

Once we take all of our agency taps and everything else, that's probably going to leave about a little over a million dollars, between $1 million and $2 million, and we expect to fund additional state implementation grants with most of that money.

We are already funding six state implementation grants, and these are states who already have a plan in place, who already have a coalition in place, and were ready to launch. And so, we are very, very happy with those six, and we are hoping to expand that by a couple of states, depending on availability of funds.

Along with that, we have just launched our evaluation activity with Insight, and I can share that plan with folks if they would like to see it, and we support two coordinating centers, one with AUCD, to help support the training effort through Lend, and one through the Association of Maternal and Child Health Programs, to help support states as they develop coordinated plans for services, specifically, for services.

Dr. Rice: This is Cathy Rice from CDC, and if it's all right I'll go ahead and go.

In terms of for this committee services activities, it's a smaller part of our activities. We are ongoing with our surveillance and monitoring programs, as well as a large risk factor study called the SEED Study. So, those are in the field and continuing to work with families and collect data on who is affected with autism, and who is at risk.

In terms of the Services Subcommittee, our primary activity is the Learn the Signs, Act Early campaign, which was mentioned several times, and we are partnering with HRSA and MCH Bureau to sponsor Act Early summits of coordinating and getting increased collaboration among various regions and within states. And, you'll hear more about that at our next IACC meeting when we present together on that.

Ms. Blackwell: Gail, are you still there?

Dr. Houle: Yes, yes, I am.

Hi, this is Gail, and I wanted to say that probably most people have heard that education, special education, Parts B and C of IDEA have received increased funding through the ARRA, and there is a chart on the web site, ed.gov that will let you know what your state is getting in an increased allotment. And, all the money is going to the state to flow through to the local programs in schools. So, that's very good news.

The total for Part B, children six through 21, the total additional funding will be $11.3 billion, and preschool will get an additional $400 million, and the Part C, birth to age three, will get $500 million additional appropriation this year. And, the ed.gov web site, we are just going to e-mail this, they are to distribute $44 billion in 30 to 45 days. So, our office is working very hard to get the funding out to the states.

What it will be used for is, the guidelines are on the web site, but, basically, it boils down to anything that could be paid for, or any use of funds that could be used under IDEA Part B or Part C, is something that the ARRA funds can be used for.

And, there are to be additional funds, these funds are funds that are to be used to increase the level of services available to children, and states must maintain their maintenance of effort that they already have under the program. So, they are not supplanting funds, they are additional funds.

The other thing is that our Technical Assistance Center, Frank Porter Graham is now accepting state applications to receive intensive state TA and training for personnel serving children with autism in their state, and they enroll, I think it's three additional states each year for intensive TA on-site training institutes, extra materials. So, that's available to states to apply for right now through the Frank Porter Graham web site.

That's it.

Ms. Blackwell: Thank you, Gail.

Dr. Houle: You are welcome.

Ms. McKee: I always laugh when you do this to me, Ellen -- this is Christine.

I'm a parent of a child with autism, and I don't have an agency.

But, let's see, what's going on right now, I'd be really interested, Gail, on the Department of Education putting together a presentation for the IACC or the subcommittee. I think parents are hungry for information.

We just finished up our alternative Maryland State Assessment. I have a third grader, and lots of parents have questions about what that's all about, and the No Child Left Behind.

Dr. Houle: Okay.

Ms. McKee: That, and the other questions out there right now are really about inclusion, and meaningful inclusion for our children.

I live in a school district that focuses a lot on inclusion, but maybe not so much on meaningful inclusion. I hear stories from parents all the time that, you know, my child is included in the classroom, sitting behind the teacher, and can't see the boards or anything else, you know, a table full of children handed a worksheet that all the other children work on, and, you know, it's just sitting there and nobody even tries to engage the children in the worksheets.

And so, there are lots of those kinds of stories, and I don't know what guidance is out there with the IDEA about how that inclusion is to take place, but I know that there are lots of parents with those types of concerns as well.

That's all for today.

Dr. Johnson: Hi, this is Jennifer Johnson with ADD, and in terms of ARRA, our agency, ADD, did not receive any direct funding under that, but the agency in which we are housed, ACF, the Administration for Children and Families, did receive a significant amount of money under ARRA, and they are in the process of getting those funds out.

So, for those like Head Start childcare are affected by that. So, hopefully, we'll see some increase in services in those areas.

In terms of our specific programs in the Fiscal Year 2009 appropriations, our programs did actually receive an increase in funding, so we are hoping that they will be able to engage in some joint activities in the states as a result.

Our UCEP program, in its appropriations language, we are, actually, authorized to fund a partnership or partnerships with minority-serving institutions. So, we'll see what happens with that.

And, there is a bit of crossover in what was mentioned earlier by MCH and CDC in terms of what they are doing related to the Learn the Signs, Act Early, and the LEND grants, because many of our university centers are engaged in those activities, and many of them have the LEND grants and those that are focusing on the autism training. So, they are deeply engaged in that work.

Mr. Grossman: This is Lee Grossman, with the Autism Society of America, and we, too, have not received any ARRA monies, but, certainly, are willing to accept them. If you need a repository, we're happy to service such.

I guess I'll focus my comments just on what's happening in April. April is Autism Awareness Month, and it's going to be full of activities, literally, things happening every day around the Nation to celebrate autism and bring awareness to this condition.

And, last year it took on a global perspective as well, and April 2nd, which has no coincidence with the fact that it's my wife's birthday, although she gives me credit making that day World Autism Awareness Day, is going to be celebrated at the United Nations. And, there will be an event on April 1st and April 2nd to commemorate that. There have been declarations that have already been issued by the Secretary General, Temple Grandin will be presenting an event on April 1st, and on April 2nd there will be a panel of people from around the world talking about autism as a global human rights issue. I'll be on the panel on April 2nd.

On the 31st -- excuse me, the 30th, the United States has sponsored a worldwide webcast that will be broadcast from Canada, D.C., Philadelphia, Dubai, and a few other venues, and it will be a three-hour webcast of various people on panels, and Gail is going to be on the D.C. one. I'll be on the D.C. panel as well, talking about, I believe the central focus of this is education.

And then, everything else that's going on, that's just the first two days of

April, and you'll be hearing and seeing events around the country related to Autism Awareness Month, and much of it, I think what our chapters are doing, are focusing on state capitols and getting awareness and advocacy efforts launched there.

There is a very high probability that in the next couple weeks there will be two major pieces of legislation dropped on autism in Congress, and we will, obviously, keep everybody well informed on those as they happen.

Ms. Blackwell: This is Ellen Blackwell.

CMS is, actually, impacted by two giant pieces of legislation, the Children's Health Insurance Program reauthorization, and also the ARRA.

For us, I think it was mostly getting the money out to the states very, very quickly, because Medicaid is a program that is driven by a Federal/state partnership funding match, what the Stimulus Act does is, essentially, temporarily increase the amount of funding that's available to states.

As I said in November, states are juggling with the fiscal climate, and even though they are, I'm sure, welcoming the temporary increase in funding that's available to them through Medicaid, typically, it runs about 50 to 78 percent depending on the state formula going forward, because it's a temporary match, we don't really know how Medicaid programs will be impacted. So, there are a lot of questions, I think, about the long-term sustainability of some of the, for example, home and community-based waiver programs that are optionally running in our state.

So, we'll see what happens.

We also have one interesting demonstration that really has not gotten underway yet, the Money Follows the Person Demonstration, and, you know, it has really been a little bit slow to get it running. We had a conference in Baltimore, where we brought in all the states that received grants a few weeks ago. It was, actually, a great conference. This is a demonstration that speaks to take people out of institutional settings and safely return them to home and community-based settings, and, you know, it's really great. The Congress gave us a lot of money, and it's just that states are so overwhelmed, I think, with state staff with a lot of the other things happening which are a little bit distracting. But, the states that have the grants are very excited, and that program could, certainly, impact some people with autism who are either at hospitals or ICF/MRs, or -- why can't I think -- nursing homes.

So, actually, there are many people with mental illness, as we know, that are living in nursing homes, and, certainly, could be some people with autism among that group.

So, I'm going to pass the mic to Larke and let her talk about SAMHSA.

Dr. Huang: Okay, this is Larke, and SAMHSA did not get any dedicated funds from ARRA, but we are working with some other agencies on seeing how we can do collaborative programs through the Secretary's $650 million, which was for prevention and wellness funds.

In terms of programs where we may pick up some, particularly, children with autism, that's, primarily, our Systems of Care Program, which did well in the budget again, it's funded at $104 million a year, and our new program we started last year called "Project Launch," which is focused on zero to eight children, young children and their families, and which we, actually, have a couple of grants out to Maternal Child Health programs in the states. We are doing early screening, early wellness, focused interventions, picking up problems earlier on for earlier intervention.

We are thinking of also making Learn the Signs, Act Early available to the six states who were funded last year through that.

We got an increase of $20 million to expand that program, maintain the current cohort, and add another cohort, and we are pleased with that.

Those are probably -- oh, and then we have a new program coming out on what we call the transition-age youth, and that's the 18 to 25 year olds who are often aging out of children's services, pediatric care, foster care, into adult services. And, we have a small grant program that's going to go out for that in that particular.

We have in the past, when we had that program several years ago, it ended, didn't get funded last year, we did have some youth in there, along with autism, but again, it's not a dedicated focus on that, but sometimes we get those kids and families in the program.

That's probably our main program.

Ms. Blackwell: Okay. Does anybody have anything else?

Lee, do you have anything further? No?

Mr. Grossman: Just to thank everybody for coming and for participating.

I think we are making progress here, and we are feeling our way because it is such a big issue, but, certainly, we are moving the ball down the court, which is most impressive.

And, thank you all for being here and being involved.

Ms. Blackwell: Yes, let us schedule another meeting. I guess what I thought, and I guess Lee thought, that we had a meeting scheduled for April 29th. I think our plan was to meet for a round at the next IACC meeting.

Do you remember, Christine?

Ms. McKee: Is April 29th the Autism Resource Fair?

Mr. Grossman: I don't know. Ms.

Blackwell: I think a week day.

Mr. Grossman: It was like Wednesday, something like that.

Ms. Blackwell: Well, what do folks want to do? I mean, our next full IACC meeting is May 4th.

Mr. Grossman: May 4th.

Ms. Blackwell: And, do you know what day of the week that is?

Mr. Grossman: That's a Monday.

Ms. Blackwell: Monday, May 4th. So, this is March 23rd, do we want to meet again the end of April, before we have the next full meeting, or do we want to wait until after the next full meeting? What do you think?

I think we are ready to talk about what we talked about today, tell them what our focus is going forward.

So, maybe meet mid May, does that sound like a proposal? Okay, so we'll work with Susan to get a date, and, Bonnie and Cathy, we'll have you on there for at least an hour. So, we'll plan on getting -- you know, you guys sending some materials to NIMH, so you'll have a presentation that we can share with the public, and Lee and I will start plotting to how to squeeze information out of other Federal agencies.

Okay, so thanks everyone for participating, and to the folks in the room and also on the phone.

(Whereupon, the above-entitled matter was adjourned at 2:55 p.m.)