

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

SERVICES SUBCOMMITTEE MEETING

WEDNESDAY, DECEMBER 10, 2008

The Committee met in Conference Room 7 of Building 31, 6C, National Institutes of Health, Bethesda, Maryland at 2:00 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

DELLA HANN, Ph.D., Office of Autism Research
Coordination, National Institute of
Mental Health

ELLEN W. BLACKWELL, M.S.W., Centers for
Medicare and Medicaid Services (via
teleconference)

LEE GROSSMAN, Autism Society of America

ERIN BRYANT, M.J., Office of Autism Research
Coordination, National Institute of
Mental Health

JENNIFER DRIER, Office of Autism Research
Coordination, National Institute of
Mental Health

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

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PRESENT (continued):

ANNE SPERLING, Ph.D., Office of Autism
Research Coordination, National
Institute of Mental Health

DENISE JULIANO-BULT, M.S.W., National
Institute of Mental Health (For
Dr. Thomas Insel) (via teleconference)

GAIL R. HOULE, Ph.D., U.S. Department of
Education (via teleconference)

CHRISTINE M. MCKEE, J.D. (via teleconference)

CATHY RICE, Ph.D., National Center on
Birth Defects and Developmental
Disabilities (For Dr. Edwin
Trevathan) (via teleconference)

STEPHEN M. SHORE, Ed.D., Autism Spectrum
Consulting (via teleconference)

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

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TABLE OF CONTENTS

Call to Order and Introductions Ellen Blackwell, M.S.W. and Lee Grossman	4
Discussion of Services Presentation at Full Committee Meeting on November 21, 2008	8
Approval of Minutes from October 10, 2008 Services Subcommittee Meeting	21
Discussion of Responses to Request for Information	22
Discussion of Integration of Request for Information and ASD Roadmap	25
Discussion of Future Speakers	35
Introduction of Dr. Susan Daniels	40
Review of Action Items	45
Adjournment	48

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PROCEEDINGS

2:03 p.m.

Mr. Grossman: Hi. Welcome. This is Lee Grossman. Welcome to the Interagency Coordinating Committee Service Subcommittee Meeting.

We're going to do some introductions here. And I just want to remind everybody that when you do talk and comment, please -- as this is being recorded -- identify yourself.

And it also helps us here in the room know who is speaking and we can keep track of this.

So we'll go around the table to introduce who's here in the room.

Dr. Daniels: Susan Daniels, Office of Autism Research Coordination.

Dr. Sperling: Anne Sperling, Office of Autism Research Coordination and NIMH.

Ms. Dreier: Jennifer Dreier, Office of Autism Research Coordination.

Dr. Schwechter: Azik Schwechter,
Office of Autism Research Coordination, NIMH.

Ms. Bryant: Erin Bryant,
Office of Autism Research Coordination.

Dr. Hann: Della Hann, Office of
Autism Research Coordination.

Mr. Grossman: And those of you on
the phone?

Dr. Strickland: Bonnie
Strickland, Health Resources and Services
Administration.

Dr. Shore: And Steven Shore,
Autism Spectrum Consulting. And I'm a
Professor at Adelphi University.

Ms. Juliano-Bult: Okay. Denise
Juliano-Bult, National Institute of Mental
Health, Services Research and Clinical
Epidemiology Research Branch.

Ms. Blackwell: This is Ellen
Blackwell, Centers for Medicare and Medicaid
Services, Disabled and Elderly Health Programs
Group. I'm also the Co-Chairman of the

Services Subcommittee with Lee.

Ms. McKee: Hi. I'm Christine McKee, parent of a young girl with autism.

Ms. Blackwell: Excellent. It appears that we have a quorum.

Mr. Grossman: We are one shy of a quorum.

Ms. Blackwell: Are we one shy of a quorum?

Dr. Hann: At this moment in time, there is one, two, three, four, five, six of you.

Ms. Blackwell: Correct. Thank you. We are expecting Gail Houle from the Department of Education to call in.

Mr. Grossman: And Cathy Rice from CDC. She said she'd be a little bit late.

Why don't we jump into the agenda. Did everyone receive the materials for this meeting?

Dr. Shore: I don't think I did actually. I've been wondering about them. Is there someone who can dash me an e-mail?

Dr. Hann: Yes, Steven. We sent you an e-mail about a day and a half ago. It provided the agenda and so forth. But we can send it to you again.

Ms. Blackwell: I'm going to forward it right now, Steven.

Dr. Shore: All right. I have the agenda. But that's about as far as it goes.

Ms. Blackwell: Okay.

Mr. Grossman: Well, anyway, I want to thank everybody for being here. I know the meeting has been complicated with the addition of the IACC meeting that's going to be held this Friday. And I know it's burdensome on all our schedules to try to fit two of these meetings in in one week. But I thank you for being here and taking the time to be involved.

Ellen and I have discussed the

agenda. We think that we can pretty much go through this in a rather rapid manner.

And so what we wanted to do first was to get people's feedback on the services presentation that was done at the last IACC meeting. Typically what I'd like to hear is if people feel that it was impactful and it made a difference, or if there's something that we should have done differently or should you going forward. Because actually I think because of all our schedules being so busy, we haven't had any adequate follow-up or feedback since then. So whatever you can provide or any insight you want to provide would be great.

I know Steven, you weren't there. So

-- Dr. Shore: Yes. But I can make up

--

Mr. Grossman: Yes. You can make something up.

Dr. Shore: A bunch of nonsense, I suppose.

Ms. Juliano-Bult: Well, you could say it was great, Steven.

Dr. Shore: Okay. Yes. It was wonderful. And we should do everything that was included. Plus we should do the following.

Ms. Blackwell: Well, I know, Denise, you were there.

Ms. Juliano-Bult: Yes.

Ms. Blackwell: What were your impressions?

Ms. Juliano-Bult: Well, the section with the slides in which you went over sort of the comprehensive view of what it's like to try to seek services I think was the most -- was really the most comprehensive compilation of that picture. And I really had the impression that Tom Insel had not really grasped the complexity of it. I think his comment was it's easier to map a gene, or something like that. I think I understand.

So it seems to me that that's a point that probably -- it's sort of a cohesive chunk of information that probably will continue to be useful for folks to know that side of the issues that families with someone with autism have to face.

Ms. Blackwell: Well, when I undertook putting that presentation together, I was really hoping that someone had already done it.

Ms. Juliano-Bult: No. No.

Ms. Blackwell: And unfortunately that wasn't the case. So I really approached it from kind of an independent perspective. And I've spoken with Azik. Unfortunately, we can't post it on the website. But if anyone would like a copy of it, they need only to send a request to the committee through the IACC website, and we'd be happy to forward. Is that correct, Azik?

Dr. Schwechter: Yes, that's

correct. All they need to do is just e-mail IACCPublicInquiries@mail.nih.gov and we can send it out.

Ms. Blackwell: And what Denise is referring to is a presentation that really talked about how a person with autism of any age could receive services and support through various public and private programs.

Dr. Schwechter: Yes. Just let me know whatever talk that she wanted and I can get it to her. I guess, Denise, you can contact me directly.

Ms. Blackwell: I think we got in a lot -- seven speakers in one afternoon. So I'm really pleased that we came through timely and hopefully the committee will want to hear more in the future about services.

And we suggested that to the committee at the full meeting. Nancy Thaler was there. Nancy is the head of -- represents all the development disabilities directors in

the United States. And also Ann Kohler who is the head of the Medicaid Directors group.

So the fact that those folks are very interested in IACC activities is a good thing.

Ms. McKee: Yes. I thought that the -- this is Christine.

I thought the presentation was wonderful. I mean, everyone did a great job. We were short on time and trying to condense it down.

I liked all the focus. The guy from California, he was great. I mean, I think that he had the energy that that room needed at that point in the day. So I thought that was wonderful.

There are so many areas to touch upon that it's so hard to present all of the information. I'm happy that they're going to continue to allow the Services Subcommittee to present at IACC meetings. I think that's important. I'd love to see -- and Gail's not

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on the line -- I'd love to see something from the Department of Education talking about the services for the younger kids -- the kids under 21 -- or the lack thereof these days.

So I thought it was a wonderful, wonderful first presentation. And I hope we get the opportunity to do more.

Dr. Houle: Hi, Christine and everyone. It's Gail. I'm on the line now.

Ms. Blackwell: You just gave us our quorum, Gail.

Dr. Houle: Oh, good. Good. Thank you.

Dr. Rice: Hi, Ellen. And this is Cathy Rice. I joined a while back.

Ms. Blackwell: Oh, great. Thanks, Cathy.

Well, Gail, would you be willing to attack perhaps a future presentation on how people with children with autism -- maybe go into a little more depth than I did. I felt like I barely scratched the surface on

education or Medicaid.

Dr. Houle: Certainly. I would be happy to.

Ms. Blackwell: There you go, Christine.

Ms. McKee: I think that would be wonderful. I think for all the members of the IACC and the other people in the audience to hear what's going on how and the efforts that are being made and where there are still gaps and what the focus of the Department of Education is at this point.

Dr. Strickland: This is Bonnie. I think at one point when we were planning the sessions the last time, we talked about deliberately not talking about the Agency initiatives at this point in time, but to provide a broad context for services from a community perspective. And we were going to try to make sure though that sort of in a rotating basis that the Agency initiatives could be highlighted in some systematic way.

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Ms. McKee: When the IACC -- in the mornings when people would go around and introduce themselves and the agencies had an opportunity for a ten- or 15-minute -- less than that -- maybe a ten-minute update on what was going on at their agencies. It doesn't seem like there's a lot of that right now.

Ms. Blackwell: Della, would you like to address that? Because I know that -- I think that is one of our responsibilities in the Combating Autism Act. And I know that the IACC is focused so much on completing the strategic plan that we -- as Bonnie pointed out -- really haven't had a chance to do as many updates as used to in the past.

Dr. Hann: Yes, I hear you. I hear exactly what you're saying. And I do think that the last meeting and certainly the one for the 12th, since it was an unplanned meeting, that hearing from the different agencies was not something that was necessarily on the agenda.

But it does need to come back. And it needs to be on there because a major task -- there are several major tasks that the Combating Autism Act outlines. One of them is the monitoring of the federal activities with regard to autism. And that's where those agency updates become quite critical.

Mr. Grossman: And please, there has been a request from the room again. Before you speak, please identify yourself.

What is the feeling of the group? Did we -- because what Ellen and I had talked about what we wanted to accomplish on that day was to give the committee a sense of the urgency of what is happening in the services community and what is perhaps happening in families' lives.

Do you think that was adequately communicated? Or if there's something different that we should have done on that day? I'm looking for some guidance here

in terms of future presentations or if there's any need or any reason to go back and clarify what was presented at the last meeting.

Dr. Strickland: This is Bonnie.

I agree with everyone that the presentation was wonderful. And it came at a good time after a very tedious morning.

And the other thing is, you can't do everything -- can't cover the entire landscape in a short period of time. And I think that there was a focus sort of on older kids and growing into adulthood. And I think for a very good reason -- it's really bad for people to age out of the system, or inadequate. We'll just call it that.

So I think that the session was well done. I think it captured the attention of the committee members.

I do think that we need more presentations like that. And I think we do need to also focus on the focus of the Combating Autism Act at one point, which is

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the younger kids.

But I think it was entirely appropriate to start out the very pressing and critical issues facing the community right now.

Dr. Rice: And this is Cathy Rice. I would just add I thought it was an excellent presentation and really wonderful insights and speakers. And the only thing I think I would add in terms of putting it on the usual agenda for the IACC is more clarity and well, what is the Services Subcommittee asking of the larger committee? Besides awareness, what are we trying to achieve? And I think that that would be something I think we should agree on and kind of have that focus in mind for the next round of presenting sort of services issues to the larger committee.

Mr. Grossman: And I think that's an excellent point, Cathy.

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Ms. Juliano-Bult: Yes. This is Denise. I think that's a good point too.

Dr. Shore: This is Steven Shore. Clarity is always appreciated and important.

Ms. Blackwell: This is Ellen. I think with this first opportunity -- the two and a half hours that we had -- our goal was to really try to cover as much ground as we could, and get the committee somewhat grounded in what's happening in the services arena. So it was kind of like a shotgun effect. We tried to hit on a lot of things with the little bit of time that we had. So in that respect, I think we did achieve our mission.

But in the future, you're absolutely right. We need to pick our speakers carefully and think exactly what -- I think part of our goal is to shine the light on what's happening with services and support. So that's always important. And there are

plenty of places to shine that light.

Dr. Rice: And just to clarify -- this is Cathy again. I thought that that goal was clear and wasn't really achieved in the last meeting. And so I was just talking about forward.

Mr. Grossman: And I think that's great, Cathy, because that's I guess somewhat the unanswered question that I've had in the role of the Services Subcommittee. This is Lee by the way. I'm the one that's isn't following my own rules here. But we haven't defined clearly what that is that the Services Subcommittee is asking of the full committee. And we've kind of been moving around the boundaries here trying to find our footing which I think is ap propo to leading us to the rest of the agenda.

And hopefully we can get some clarity on that before the next full IACC meeting which I guess is in March, and that we can come --

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Dr. Hann: February.

Mr. Grossman: February. But that we can come together with some specific requests for the IACC on how we can move this whole agenda forward.

With that in mind, let's move to the next point, unless anybody has anything else to add. Della has something to add.

Dr. Hann: Yes. This is Della.

All of you fairly recently received copies of the minutes from the previous Services Subcommittee meeting. And I was hoping that we could have a brief review of that and see if we can gain the Committee's approval for those.

Ms. Blackwell: Did everyone receive a copy of the minutes from the October 10th call?

Dr. Schwechter: This is Azik. I e-mailed them to everybody a little while ago. So if you're on your e-mail, you can look and you will see an e-mail from me.

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Dr. Shore: Yes. This is Steven Shore. I got mine. They came in at 1:57.

Ms. Blackwell: Does anyone have any objections to approving the minutes from the October 10th meeting?

(No audible response.)

Ms. Blackwell: I think the minutes are approved, Della?

Dr. Hann: Thank you all very much.

Ms. Blackwell: Okay. Thank you for doing that.

Mr. Grossman: Ellen, do you want to talk about what some of the ideas on the RFI?

Ms. Blackwell: Well, let me share with you a conversation that Lee and I had recently about the RFI.

I don't know how many of you have had a chance to go to the IACC website and look at the comments themselves. But I think that Dr. Sperling did a great job on putting

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together sort of a first pitch at what sorts of categories these might fall into. But Lee and I are thinking that maybe the two of us might want to sit down together and go back a little bit further than Anne's summary and look at the comments themselves and just make sure that we're good with the categories that the comments fall into.

Do you want to talk a little bit about that, Lee?

Mr. Grossman: Well, yes. I mean, when we look at that, we feel as though we probably should flush out a little greater some of the detail in terms of the categories. Right now, for example, we have healthcare/treatment. And that would be a category that we probably could define greater to see if there's services or interventions that would fit under that category.

When we've looked at how some of the responses were categorized under education, it seemed as though they probably

would be better categorized under a heading of professional training, or --

Ms. Blackwell: We call it provider qualifications here.

Mr. Grossman: Yes. Provider training.

Because like in mind when I think of education, I'm thinking of public school or school-age children education, or services that would be provided by the Department of Education. And some of the RFI responses seemed as though under education would better be defined as education to providers or others. So what Ellen and I have decided that we would do is just meet -- sequester ourselves for a day -- and just go through it. And kind of peel out of the responses and perhaps come up with some new categories. And then bring that back to Della and her team, as well as back to the Committee to see if you're in agreement with what we've come up.

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Ms. Blackwell: And I think that part of our goal in doing that is what we've talked about before which is to integrate what we got out of the RFI into the old roadmap. And Lee had a proposal this morning that I thought was really good where we can all -- I know we keep harkening back to the roadmap -- but Lee, I thought your idea was great. Can you talk about what we would like the Subcommittee members to do for us?

Mr. Grossman: Yes. I wish I would have save that e-mail that I sent out.

Ms. Blackwell: Hold on. I actually --

Mr. Grossman: If it is, then you can read it, because it's probably better articulated there than what I can say.

Ms. Blackwell: Okay. Let me read the note that Lee sent this morning, because I think he did a great job summing this up, that we would like the Subcommittee

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members to review the roadmap" -- that's the document was issued on May 16th, 2005, and provide comments to us by the end of January on what your agency or what your interests are respective to the roadmap and what you would like to do above and beyond what's in the roadmap. And most importantly I think this last item, what is and what is not relevant in this version of the roadmap.

So if we get that, we'll be in a better position to take the comments from the RFI and try to figure out how to update this roadmap. I mean, I personally think a lot of this is outdated or it's just not quite phrased exactly the right way. So, it would really be helpful for us to solicit your input so that we can truly start to update this thing.

Mr. Grossman: And we're coming at this from the belief that this is a good foundation to work forward from -- the roadmap is. And instead of recreating the

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wheel, let's see what the wheel has to offer. And if we have to modify it -- and which I'm sure we will -- then let's do that with the information that we've gotten from the RFI and what the agencies believe are provided. I think from that we'll have a better sense on what specifically we can begin to ask for from the full IACC committee. Right now, it is so complex. It is so broad -- the services agenda -- that as the presentation were, we could ask for the world and it's just going to add to everybody's frustration if we're not able to deliver on some specifics.

So with that said, that's a suggestion or a recommendation that we're making out to the Services Subcommittee is that by the end of July that everybody takes a look at it --

Ms. Blackwell: July?

Mr. Grossman: January.

Ms. Blackwell: Yes.

Mr. Grossman: My mind is in July. When it gets cold, I start thinking about summer.

Ms. Blackwell: And I think it would actually help. I do this routinely in my job. You're -- just say okay. Strike second paragraph, page one, page whatever. Actually they do have page numbers on them. They're just very faint at the top. But if you think that these challenges are not appropriate, or these recommendations are not appropriate, then just say. I think we need to identify at least what's relevant and what's not relevant, and what's missing.

Dr. Hann: So to facilitate this discussion a little bit since I'm looking at a calendar for January and knowing too that the full IACC meeting will be in the first week of February, would it be possible for if you all decide to do this that you would have comments to Lee, Ellen and myself by the 23rd

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of January?

Ms. Blackwell: I think so.

Dr. Hann: Great.

Ms. Blackwell: That would be so wonderful and very, very helpful to us as we try to take another look at the RFI and see where we're going with this roadmap.

Ms. Juliano-Bult: Do you want the feedback on an electronic version with the track changes?

Ms. Blackwell: That would be fine. That would be fine, Denise.

Dr. Hann: Actually Denise and others, the roadmap currently exists as a pdf.

Ms. Blackwell: Oh.

Dr. Hann: And unfortunately, I do not have a Word version. All I have is a pdf version.

Dr. Schwechter: We actually don't have -- I haven't found a Word version. But the roadmap is linked from the IACC website as a html. So you can copy that as anything you

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want to.

Ms. Juliano-Bult: Lee, do you have a Word version of this?

Mr. Grossman: I converted it to word. But it's not very clear.

Dr. Hann: That's the problem with doing a backward transfer like that. So unfortunately, I'd be happy to provide you the Word, but I just don't think it's going to be feasible.

Ms. Juliano-Bult: Well, do you want a hard copy with comments?

Ms. Blackwell: What I would suggest, Denise, is just do it by page.

Ms. Juliano-Bult: Okay.

Ms. Blackwell: That's the way I usually --

Ms. Juliano-Bult: Describe it by.

Ms. Blackwell: -- page one, paragraph three or whatever it is. Page 11, recommendation.

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Dr. Hann: Yes. And another way too -- not to get too far into the weeds -- you can do copy. You can copy. It comes out as an image. But you can take like a paragraph if it's one that you really want to say this is the one I want to re-word. You can copy that and put that into a Word document. It'll come in like a figure, so you can't like change it. But at least we know then -- everybody will know what paragraph you're talking about.

Ms. Blackwell: Okay. Okay.

Ms. Juliano-Bult: And you said by January 23rd?

Dr. Hann: Yes.

Ms. Juliano-Bult: Okay.

Dr. Hann: We'll follow up after today's meeting with the round-up essentially of the various action items from today's meeting. But I just wanted to get that out there since so many of you are on the phone.

Mr. Grossman: And looking at

the agenda, that really addresses most of our agenda for today, which is to look at the roadmap review status and integrating the RFI in the roadmap.

Ellen and I are going to try and meet before the end of the second week of January to go over the RFI. And we'll probably use that time to also put our minds together on the roadmap I would imagine and again to make suggestions to the committee on what the RFI is adding to the current version of the roadmap. Does that sound right, Ellen?

Ms. Blackwell: Well, I think it might be after -- we can start looking at the comments sort of towards the end of January and then once we get the -- we can start looking at the public comments ourselves sometime in January. And then we'll have the group comments on the roadmap. So we should be able to get ourselves together hopefully possibly before that IACC meeting in February.

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But we'll shoot for that. How does that sound?
I don't know if we'll have anything ready for
the full committee before then.

We do have an exciting
announcement. Our March 26th meeting which will
be held at the Humphrey Building in Washington
will feature Captain Robert DiMartino.
And you've worked with Captain
DiMartino more than I have, Gail. Would you
like to maybe give a little introduction of who
he is and what he's doing -- I mean, as much as
you know?

Dr. Houle: This is Gail. Is
Robert DiMartino on this call?

Ms. Blackwell: No.

Dr. Houle: If he is, he could
speak.

Ms. Blackwell: No. Unfortunately
only the IACC members can talk on the call.

Dr. Houle: Okay. Okay. Well, I

had not prepared an introduction for Robert DiMartino. But I have worked with Robert. Can you hear me?

Ms. Blackwell: Yes.

Dr. Houle: I don't know why I was getting an echo. This is Gail again.

I have worked with Robert in the past. And my understanding is that the Department of Defense has at least one initiative going on in the area of evaluating services for their dependents who have been diagnosed with autism, and also funding and carrying out some model demonstration projects for military dependents with autism in the Department of Defense schools. So that's what I'd like to -- I'd really be interested in hearing how they're coming along with that and having Robert report to us will add another piece to the services work that's going nationally that we haven't heard from yet.

Ms. Blackwell: And this is the -- by the way, this is Ellen.

This is a grant-funded program. So I did not include it in my presentation because the Congress hasn't re-authorized it to continue.

But Captain DiMartino is the Director of the Behavioral Medicine Division at Tricare. So I think all of us could learn from his experiences particularly with early intervention services. And we'll be really interested to hear what Captain DiMartino has to say. That's pretty exciting.

Dr. Houle: Yes. This is Gail Houle. I think it is. They've done some work. And it's my understanding that this was part of last year's Defense Authorization Act. We would probably know the actual legislation that provided them with the directives.

And it's my understanding that they're going to be issuing that report to Congress this month. So that will provide some more information that Dr. DiMartino will

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be able to provide to us.

And it's always interesting for education and very vital for us to work hand in glove with the military schools and the system of military schools that are out there in this country and overseas.

Ms. Blackwell: So again, that's March 26th at the Humphrey Building in Washington. Okay. Great.

Mr. Grossman: Any other questions or comments or issues that people want to bring up?

(No audible response.)

Mr. Grossman: Hearing none, then Della, are you going --

Dr. Hann: I just want to mention one thing.

I think I was just conferring with Azik. We can't remember the dates of the February meeting.

Dr. Schwechter: The February meeting?

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Dr. Hann: Yes. The Subcommittee is also supposed to have a meeting towards the end of February.

Mr. Grossman: Just one second.

Dr. Hann: Lee's looking up the date, which is very helpful. Thank you.

And then there's the meeting on the 26th of March that Ellen just spoke to. And I think it would be helpful to know if the meeting -- it sounds like the meeting in March, we will want to have it a face-to-face meeting if Captain DiMartino will be there as a presenter. But it would also be helpful for us to know if you anticipate the February meeting to be face-to-face or just to be a Webinar.

Mr. Grossman: Twenty-fourth.

Dr. Hann: Thank you.

So February 24th is the next Services Subcommittee meeting.

Mr. Grossman: And it's a

morning meeting from -- I have it scheduled from 9:00 to Noon -- 9:00 a.m. to Noon.

Ms. Blackwell: And I think we had talked about possibly having it at SAMHSA, but I'm not certain of Larke's schedule, when exactly she comes back. Larke is on a rotation to the Centers for Disease Control in Atlanta. She may or may not be back in February. So --

Dr. Hann: Right. And so --

Ms. Blackwell: -- I'm thinking maybe we should convene that meeting electronically. What do you think, Lee?

Mr. Grossman: The one on the 24th?

Ms. Blackwell: Yes. Or would you rather have a face-to-face meeting?

Mr. Grossman: I think my druthers are to have it as a face-to-face because by then we'll have all the comments in from the RFI and the roadmap. We'll be able

to sit down as a committee and review that.
And hopefully start chiseling out exactly what
Cathy Rice brought up in terms of what we should
be then directing or suggesting to the full IACC
for action for a committee to follow.

Ms. Blackwell: So perhaps should we
ask OARC to schedule us a room at NIH just in
case?

Mr. Grossman: Sure.

Ms. Blackwell: Okay.

Dr. Hann: I'll do that.

Ms. Blackwell: Thank you. And I
also think I'm not sure who our designated
federal official is today. Is it you, Della?
Or is it Susan?

Dr. Hann: Thank you for that great
segue.

Actually, I'll be signing off on the
various documents. But this is sort of Susan's
first foray.

Ms. Blackwell: I was hoping

you would introduce Susan -

Dr. Hann: Yes.

Ms. Blackwell: -- to the group.

Dr. Hann: I'm happy to.

Joining us today is the new Deputy for the Office of Autism Research Coordination, delighted Dr. Susan Daniels. She's officially on board. Some of you had the opportunity to meet her at the last IACC meeting in November where she was kind enough to join us even though she hadn't officially joined the Office at that moment in time. Susan, do you want to say hello?

Dr. Daniels: Hello. It's very nice to be with you. And I'm very excited to be working with you both on the Subcommittee and the full Committee.

Ms. Blackwell: Thanks, Susan. We're really glad that you're able to be our designated federal official. And we look forward to seeing you on Friday.

Dr. Daniels: Yes.

Ms. Blackwell: And now that you're fully on board. And we also -- I said this at the last meeting, but I just want to emphasize again that the Subcommittee really appreciates the support that we've gotten from the staff of OARC. And your services have been invaluable to us. And I'm sure the full committee feels the same way. So thank you all.

And one more item. I know that

Della sent out a copy of Bonnie's article.

And Bonnie, you might just want to talk for a second about your article -- the article that you wrote with some other folks including our colleague, Peter Van Dyck.

Dr. Strickland: Right. It appeared I think in the last issue of Pediatrics. And it's data from the national survey of children with special needs, and a long time talking about that.

But that survey is a one of a kind

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survey. It's a national survey. We work with CDC National Center for Birth Defects, and specifically the National Center for Health Statistics.

And it's essentially a survey of about 40,000 children who need special health care needs national wide. And a subset of those children and youth, their parents say that they have a diagnosis of autism.

And the bottom line is -- and this is not unexpected -- but we find that parents of children and youth with autism fair far worse on many health indicators than other children and youth with special health care needs, including other children with behavioral developmental issues.

Specifically, they have far more unmet health care needs. They have far less family support. And they are far more likely to delay or forego needed health care.

We also found that there's a significant increased impact on family in

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terms of having to reduce or stop work to care for children who have a diagnosis of autism. So I don't think that surprises anybody on this. I don't think it would surprise much of the ASD community. But it's nice to have a study that actually confirm what we all know.

Interestingly enough, one of the -- and I don't know how quite to explain this -- but families who had what we call a medical home or the comprehensive coordinated source of ongoing health care -- and when I say coordinated, I mean coordinated with other community services -- those families seem to have less adverse impacts than families who did not have a medical home.

So I hope everybody gets the chance to read it. There's probably more to come.

Ms. Blackwell: Bonnie, I have a question for you. I was talking with one of my

colleagues a couple weeks ago about the medical home. And she mentioned that some folks want to call the medical home the health home.

Dr. Strickland: Yes. Well - and some people do. It's been sort of an ongoing discussion for almost -- well, as long as I've been at -- 1992.

Ms. Blackwell: Okay.

Dr. Strickland: And it's sort of a terminology that was developed by the American Academy of Pediatrics. And a lot of people just don't like that reference to medical and home. But it is sort of stuck in many communities.

But people at this point in time really don't want to argue over the terminology. They really just want to get on with what it is and more than just there's a doctor somewhere. But it's a health care system that recognizes the inner dependence of all aspects of the community and acts

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proactively to coordinate with other services in the community.

So you'll find a lot of entities calling it a health home. And I think at this point, we call it what we want, as long as we all know what it means.

Ms. Blackwell: Okay. Thank you.

Mr. Grossman: Is there anything else?

(No audible response.)

Mr. Grossman: Do you want to review the action items?

Dr. Hann: Sure.

Mr. Grossman: I'm going to have Della review the action items.

Dr. Hann: Okay. And please correct me if I didn't get it right. But what I heard is there were sort of two sets of action items.

The first is that Ellen and Lee will meet sometime before early January to go

through the RFI and consider if there are additional bins essentially that need to be created out of the RFI responses and/or different words to describe the existing bins. And that all of that information however will be brought forward to the committee -- to the IACC, and to OARC as well. But the important thing is that it becomes public.

Then the second part is that each of the Subcommittee members are to review their existing roadmap for services and identify areas that they would like either see changes or additional suggestions made, as well as potentially even talking about what progress they may know of that has gone on with some of those areas. And that information will be given back to OARC by January the 23rd.

Then all of that information will be pulled together so that it's available for the next Subcommittee meeting by the end of February, which will be the 24th. That will

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be an in-person meeting. And I do encourage people -- particularly those who don't have to travel very far -- to try to physically attend.

We will find a room some place on the wide NIH campus. It could be one of the satellites in order to facilitate parking, rather than the main campus for that. That meeting is currently scheduled for February the 24th in the morning hours, probably 9:00 to 12-ish -- something like that.

And the last thing that we commented on was that Captain DiMartino has been invited to the meeting on March the 26th. That meeting too will be an in-person meeting. And it will be held down at the Department of Health and Human Services -- the Humphrey Building -- which is on D and Independence, I think, or something streets. I think it's D or C -- one or the other. It's an alphabet.

Dr. Schwechter: We'll send all of that out.

Dr. Hann: We'll send that out. But that too will be an in-person meeting. And particularly given that there's an invited speaker, I would encourage people to turn out. As you know, when you're a speaker too, you like to see faces in the room.

That's all I heard. But please correct me if I'm wrong.

Mr. Grossman: No. That sounds right. I'm trying to think -- I was at HHS building last night. So I'm trying to remember the address as Independence and something down there -- the base of Capitol Hill. Any other comments from anybody?

(No audible response.)

Mr. Grossman: Ellen, are we ready to adjourn?

Ms. Blackwell: I think we're good. We're only adjourning until

Friday.

Mr. Grossman: Just a couple days.

Ms. Blackwell: We'll be back.

Mr. Grossman: Well, thank you, everybody.

I think the next couple meetings after we get all this information together will be quite interesting and productive. And we'll move this in the direction that we need to go. It seems like we've been dealing with a lot of housecleaning and organizing here. But I think it's all well worthwhile and we're about to make the next leap where we can actually get to some action. So thank all of you. And see probably many of you on Friday morning.

Dr. Shore: See you on Friday.

Ms. Blackwell: Okay. Thanks.

Dr. Hann: Thank you all. (Whereupon, at 2:46 p.m., the hearing was adjourned.)